Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa

by

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DECLARATION

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ABSTRACT

Schizophrenia is a chronic and debilitating mental disorder characterised by a diverse range of symptoms that may take their toll on a person's biological, psychological, and social areas of functioning. Today, it is undeniable that knowledge about schizophrenia, and its repercussions on the person diagnosed with it, has evolved immensely since the Kraepelinian era (Davidson, 2003). However, the effects of the disorder on others, who do not have the diagnosis, may not have been as vastly explored. We need to know more about the impact of the disorder on a range of people, be they healthcare clinicians, family members, or friends who have daily encounters with the person with schizophrenia. This qualitative study investigated the subjective experiences of caregivers of deinstitutionalised individuals with schizophrenia. It aimed at exploring participants' experiences of burden and coping while caring for a loved one with schizophrenia. Thirteen caregivers participated in individual semi-structured interviews and Thematic Analysis of their narratives produced 29 themes that describe caregivers' experiences. Caregivers experienced burdens in the following domains: 1) day-to-day circumstantial challenges, 2) new experiences witnessed, 3) the effect on the caregiver's social environment, 4) emotional impact on caregiver, 5) patient dependency, 6) living with a sense of obligation to care, 7) new physical activities, 8) physical strain, 9) disruption, and 10) difficulties at healthcare services. Caregivers utilised the following coping strategies: 1) having a life partner, 2) investing in their own needs, 3) religion, 4) making sense of schizophrenia, 5) fostering the positives, 6) interactional tactics, 7) being prepared, 8) cognitive-emotional processes, 9) professional healthcare services, 10) lay-care services, 11) police services, 12) financial support, and 13) social support. Additionally, this study reports caregivers' perception of the patient at home. The findings are discussed by drawing on local and international literature in the schizophrenia-caregiving domain. Caregives' reports of caregiver burden are discussed in three domains – 1) contextual challenges (e.g., age and gender), 2) experiences of objective burden (e.g., dependency and disruption), and 3) experiences of subjective burden (e.g., emotional impact on caregiver). Caregivers' coping strategies are further discussed in three domains – 1) qualities of the caregiver (e.g., religion), 2) emotional-focused coping strategies (e.g., positive thinking), and 3) problem-focused coping strategies (e.g., being vigilant, living in the moment and anticipating patient's needs in advance). Lastly, the strengths and limitations of this study, and recommendations for future research are discussed.

Keywords: schizophrenia, caregiver, caregiver burden, caregiver coping, South Africa, objective and subjective burden of care, transactional model of stress and coping, thematic analysis

OPSOMMING

Skisofrenie is ‘n kroniese en verlammende geestesversteuring wat gekenmerk word deur ‘n verskeidenheid van simptome, wat hul tol kan eis op ‘n persoon se biologiese, sielkundige en sosiale funksionering. Vandag is dit onbetwisbaar, dat kennis oor skisofrenie en die gevolge daarvan op die persoon wat daarmee gediagnoseer is, geweldig uitgebrei het sedert die Kraepeliese era (Davidson, 2003). Tog, is die effek van die siekte op ander, wat nie die diagnose het nie, nie so wyd bestudeer nie. Daar is ‘n behoefte na kennis oor die impak wat die geestesversteuring op ander mense wat daaglikse ontmoetings met die pasient het, sou kon hê; mag hulle kliniese gesondheids werkers, familie lede, of vriende van die persoon met skisofrenie wees. Die kwalitatiewe studie het die subjektiewe ervarings van versorgers van buite-pasiente met skisofrenie ondersoek. Die doel van die studie was om deelnemers se ervarings van las en die hantering van hulle omstandighede tydens die versorging van ‘n geliefde met skisofrenie te ondersoek. Dertien versorgers het aan individuele semi-gestruktureerde onderhoude deelgeneem, en Tematiese Analiese van hul stories het 29 temas gelewer wat hul ervarings as versorgers beskryf. Versorgers het las in die volgende areas ervaar: 1) daaglikse omstandigheids struikelblokke, 2) die ervaring nuwe ervarings, 3) die effek op die versorger se sosiale omtrek, 4) emosionele impak op die versorger, 5) pasiënt afhanklikheid, 6) die leef met die gevoel van verpligtheid om te sorg, 7) nuwe fisiese aktiwiteite, 8) fisiese spanning, 9) ontwrigting, 10) struikelblokke by gesondheidsdienste. Versorgers het gebruik gemaak van die volgende hanterings meganismes: 1) om ‘n lewensmaat te hê, 2) deur in hul eie behoeftes te belê, 3) geloof, 4) sin maak van skisofrenie, 5) die positiewe te koester, 6) interaksie taktiek, 7) wees voorbereid, 8) kognitiewe-emosionele prosesse, 9) professionele gesondheidsdienste, 10) leke-versorgers, 11) polisiedienste, 12) finansiële ondersteuning, en 13) sosiale ondersteuning. Verder het hierdie studie versorgers se persepsie van die pasiënt wat by die huis woon gerapporteer. Die bevindinge word bespreek deur gebruik te maak van plaaslike en internasionale literatuur in die skisofrenie-versorgings arena. Versorgers se getuies van versorgerlas word bespreek in drie domeine – 1) omstandigheids struikelblokke (bv. ouderdom en geslag), 2) ervarings van objektiewe las (bv. afhanklikheid en ontwrigting), en 3) ervarings van subjektiewe las (bv. emosionele impak op versorger). Versorgers se hanteringsmeganismes word verder bespreek in drie domeine – 1) eienskappe van die versorger (bv. geloof), 2) emosie-gefokusde hanteringsmeganismes (bv. positiewe denke), en 3) problem-gefokusde hanteringsmeganismes (bv. waaksaamheid, leef in die oomblik en om die pasient se behoeftes

vooraf te verwag). Laastens word die voordele en beperkings van die studie, asook aanbevelings vir toekomstige navorsing bespreek.

Sleutelwoorde: skisofrenie, versorger, versorgerslas, versorgershantering, Suid-Afrika, objektiewe en subjektiewe las van versorging, transaksionele model van stres en hantering, tematiese analiese

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CHAPTER ONE

INTRODUCTION

Over the years, a great deal of research has been conducted to facilitate our understanding of schizophrenia as a disorder, and how it affects the lives of people living with it. Many fields of study, including psychology, psychiatry, neuroscience, genetics, and anthropology, have contributed to the holistic understanding of the disorder (Kirmayer, Lemelson, & Cummings, 2015). Recent developments in research and practice have facilitated a sense of therapeutic optimism for individuals living with schizophrenia and have reinforced the fact that schizophrenia is not solely a disorder of the brain. Environmental, cultural, and psychological factors can have a significant influence on the disorder's onset and outcomes (Kirmayer et al., 2015). Many treatments and intervention strategies have been developed that aim to improve the patient's condition and their overall quality of life; in essence, these are resources that help the patient to cope with their diagnosis and to have a better life.

Schizophrenia has been seen as, and remains something of a puzzle. Many years ago, Emil Kraepelin, who first described what came to be known as schizophrenia, devoted a lifetime's work merely to come to a better understanding of the disorder (Stefan, Travis, & Murray, 2002). Today, it is undeniable that knowledge about schizophrenia and its repercussions on the person diagnosed with it has evolved immensely since the Kraepelinian era (Davidson, 2003). However, the effects of the disorder on those associated with people who have the diagnosis has not been as extensively explored (Stefan et al., 2002). We need to know more about the impact of the disorder on a range of people, be they healthcare clinicians, family members, or friends who have daily encounters with the person with schizophrenia.

As it will become clear in this thesis, schizophrenia is a mental disorder that introduces various challenging experiences to the patient and interferes with their everyday functioning. Pharmacological treatment, such as anti-psychotic medications, and psychological interventions may be examples of resources that may assist the person with schizophrenia to attain a better quality of life while living with the disorder. However, it is often the case that patients will need further care and support from significant others on their road to recovery after diagnosis (De Wet, Swartz, & Chiliza, 2015). In this study, I specifically chose to focus on those people – the family caregivers of the people with schizophrenia. For purposes of this thesis, the caregiver is a non-professional individual who provides the most care and support to the person with schizophrenia (Awad & Voruganti,

2008; VandenBos & American Psychiatric Association [APA], 2015). Moreover, the caregiver is the person who has been living with the patient and has been intimately involved in the care of the patient for at least one year (Kate, Grover, Kulhara, & Nehra, 2014). In my study, the caregiver was, in all cases but one, a family member of the person with schizophrenia. My thesis focuses on the caregiver's experiences of living with this disorder after a family member has been diagnosed.

It is only by investigating the often unvoiced experiences and the impact of care that we can gain knowledge and understanding about the caregiver's world – the joys and challenges. By drawing from existing literature on schizophrenia in the field of schizophrenia-caregiving, and by conducting my study, this project aimed to improve our present understanding, and to create additional knowledge, of the effects of schizophrenia on the caregiver.

In the rest of this chapter, I explore a number of schizophrenia-related topics. These sections are:

1. schizophrenia as disorder;
2. the prevalence of schizophrenia;
3. global and South African healthcare challenges;
4. the deinstitutionalisation of people with mental disorders and schizophrenia; and
5. an introduction to caregiver burden and coping.

Thereafter, the chapter presents the research rationale, the research question and objectives, before concluding the chapter.

Schizophrenia – The Disorder

Schizophrenia is a chronic and debilitating mental disorder characterised by a diverse range of symptoms. This is due to the fact that it affects multiple domains of an individual's behaviour – areas affected commonly include a person's affect, emotion, motor functioning, perception, and speech (Esan, Ojagbemi, & Gureje, 2012). Asmal, Mall, Emsley, Chiliza, and Swartz (2014) add that individuals with schizophrenia commonly display signs of apathy, cognitive impairment, fluctuations in mood, and psychosis. Consequently, schizophrenia may take its toll on the biological, psychological, and social areas of human functioning.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) the above described is caused by five core symptoms. For a diagnosis, the person should at least present with two or more of the core symptoms for most of the day, for a duration not shorter

than one month (APA, 2013). Furthermore, to make an appropriate diagnosis, the symptoms should cause impairment in the individual's important domains of everyday life functioning and, as a result, decrease their overall quality of life (APA, 2013).

The Five Core Symptoms of Schizophrenia

Delusions. The first core symptom is delusions (APA, 2013). People with schizophrenia commonly experience delusions which can be defined as unshakable thoughts or beliefs held by the person during an episode of psychosis. This, however, becomes pathological as usually these cognitions are not shared by others in the person's culture or environment. Thus, at times the delusional thoughts may deviate greatly from societal normative behaviour (Jordaan, 2012; VandenBos & APA, 2015). Delusions can take different forms such as delusions of control, grandeur, persecution, and reference. In, for example, control delusions people may believe that their actions or thoughts are controlled by external forces. Whereas in grandiose delusions, people may believe that they are superior beings – more important than others or that they hold powers that others do not; for example the ability to fly (Jordaan, 2012).

Hallucinations. The second core symptom of schizophrenia is hallucinations (APA, 2013). When hallucinating, the person with schizophrenia perceives stimuli that are inaccurate or non-existing for others who do not have the disorder. Simply put, people with schizophrenia feel, hear, see, smell, and taste things that do not exist in the normative reality (Jordaan, 2012; VandenBos & APA, 2015). An example here may be when people reply to voices that they have heard, while there is no physical input of stimuli of such in their environment.

Disorganised speech. Disorganised speech is the third symptom that determines the diagnosis of schizophrenia (APA, 2013). This results from people with schizophrenia's difficulty or inability regarding holding a thought or in concentration processes (APA, 2013). The negative effects of this may display in areas of language functioning. Consequently, individuals may verbally start a sentence with a certain topic and conclude with a completely different and irrelevant narrative.

Catatonic behaviour. Catatonic behaviour is the fourth symptom that people with schizophrenia may present with (APA, 2013). This symptom takes its toll, especially, on the motor functioning of the individual. It marks a state of stupor, which is a state of lethargy and impaired consciousness (VandenBos & APA, 2015). In a state of stupor the person does

not respond to external stimuli posed to him/her and may appear disorientated and immobile. As a result, people in stupor can be rigid and mute and only focus on the stimuli of interest to them, while other stimuli are ignored. For example, a person with schizophrenia may stare at a wall for a prolonged period of time, while people who try to get their attention cannot break through and interact with them.

Negative symptoms. The fifth core symptom displayed in schizophrenia is what the DSM-5 terms negative symptoms (APA, 2013). Whereas symptoms such as delusions and hallucinations introduce experiences that the person with schizophrenia perceives as real, negative symptoms represent the removal or decrease of certain domains of human functioning (Jordaan, 2012). The person may, therefore, not function at a level that is expected as typical or a benchmark for human behaviour (Jordaan, 2012). According to the DSM-5, people who experience negative symptoms commonly demonstrate diminished emotional expressions, also known as "emotional blunting" (Jordaan, 2012, p. 208). In emotional blunting the person lacks the emotional behaviour generally expected of a person – poor eye-contact, a toneless voice, and reduced emotional reactions are common signs of this characteristic of schizophrenia. For example, an individual with schizophrenia may fail to show happiness when there is reason for this emotion to be expressed. Other negative symptoms include avolition, which can be explained as the difficulty in starting and continuing actions. Lastly, some people with schizophrenia may also tend to react with monosyllabic statements during verbal communications. This symptom is known as alogia (Jordaan, 2012).

To add to the complexity of these signs and symptoms, the DSM-5 explains that no single symptom is pathognomonic to the disorder. Therefore, if a person for example hallucinates, it does not necessarily imply that he/she meets the diagnostic for schizophrenia, as there are other conditions, such as dementias, that also share this symptom of schizophrenia. Furthermore, each person living with schizophrenia presents with a unique combination of the five symptoms discussed above – with differences in the experience of delusions, hallucinations, disorganised speech, catatonia, and negative symptoms.

The Prevalence of Schizophrenia

Approximately 1.0% of the population worldwide lives with schizophrenia (Awad & Voruganti, 2008; Kritzinger, Swartz, Mall, & Asmal, 2011). Compared with data in wealthier countries, little, however, is known about the incidence and prevalence rates of

schizophrenia in South Africa; but in concordance with the above sources, the South African Depression and Anxiety Group (SADAG, n.d.) reports that about 1% of the South African population, of approximately 55 million people (Statistics South Africa [Stats SA], 2015), are living with this mental disorder. As will be described later in this chapter, South Africa has faced and continues to face a number of challenges in its healthcare system. Consequently, it may also be the case that many individuals who meet the diagnostic criteria for schizophrenia are misdiagnosed or not diagnosed. As a result, the prevalence rates may be higher than estimated. However, the work of Kleintjes et al. (2006) attempts to determine the prevalence of schizophrenia in South Africa.

Kleintjes et al. (2006) conducted a literature review to derive prevalence rates for various mental disorders in the Western Cape province of South Africa. In conducting this literature review Kleintjes et al. (2006) found that 17% of adults in the Western Cape met the criteria for some form of mental disorder. Moreover, from this proportion of adults 0.5% of individuals have been diagnosed with schizophrenia. It should, however, be noted that these estimates were obtained over a decade ago, and that figures may have changed in recent times. Nevertheless, according to Stats SA (2015), the Western Cape has a population of over 6.2 million people. If Kleintjes et al.'s (2006) estimates are still valid today, approximately 5 300 individuals are living with schizophrenia in the Western Cape alone, currently.

Global and South African Healthcare Challenges

Mental disorders, together with neurological conditions, represent up to 13% of the worldwide burden of disease. Interestingly, this introduces a greater burden to healthcare systems than both cardiovascular disease and cancer (Collins et al., 2011). For purposes of this text I focus on mental disorders in particular.

Many mental disorders develop and begin during youth and may therefore reduce a person's quality of life for a prolonged period of time (Patel, Flisher, Hetrick, & McGorry, 2007). Yet, up to now, cures for mental conditions have been absent or scarce, and a shortage exists in effective preventative interventions worldwide. According to Collins et al. (2011), this can be attributed to three factors. First, our limited understanding of these conditions limits effective intervention. Second, for some conditions, where effective treatments do exist, these resources are not accessible to all people in some countries. The third factor follows from the second – globally there is an unequal distribution of healthcare

resources between and within countries. In its turn, this compromises individuals' access to effective healthcare. To support this point; the World Health Organization (WHO) reports that Europe has seven psychiatrists and approximately three (2.7) psychologists for every 100 000 people (WHO, 2015). Whereas in Africa, there is less than one (0.1) psychiatrist, and less than one (0.1) psychologist for every 100 000 people (WHO, 2015). As a result, one can argue that people in Europe may have more available access to mental healthcare resource compared to individuals from Africa.

The combination of disorder-burden and human-created limitations to adequate and effective healthcare may be compounding factors that introduce a number of mental healthcare challenges worldwide. The top six challenges that global mental healthcare systems currently face are: 1) the need to identify the causes, risk factors, and protective mechanisms of disorders; 2) the need for better prevention and early intervention strategies; 3) the need for enhanced treatment and broader access to care; 4) the need for increased awareness of the global burden; 5) the challenge to build human resource capacity; and 6) the challenge to transform health systems and policy response (Collins et al., 2011).

South Africa also experiences a number of unique difficulties, which impede effective healthcare (Mayosi et al., 2012), as a result of its history of apartheid (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009). According to Coovadia et al. (2009), the apartheid regime was structured to discriminate against non-White individuals in South Africa – while the majority of the country's population consisted of non-White individuals. Consequently, today, the effects of the apartheid burden still surface in the high levels of socio-economic inequality, poverty, and unemployment and low wages that mark South Africa (Mayosi et al., 2012). These socio-economic conditions may have contributed to the challenges that South Africa's healthcare system currently face; thus they cannot be ignored.

According to Human Rights Watch (HRW, 2011) and Lund, Petersen, Kleintjes, and Baha (2012), South Africa's healthcare system, specifically, encounters various challenges that, undoubtedly, take their toll on effective healthcare and mental healthcare delivery. First, the country has a shortage of mental healthcare clinicians (HRW, 2011; Lund et al., 2012). An example of this shortage is that South Africa has 670 enrolled psychiatrists; of whom 217 are situated in the Western Cape (Medpages, 2016a); and 2 583 registered clinical psychologists, of whom 727 practise in the Western Cape (Medpages, 2016b). Therefore, assuming all these registered personnel are practising in the healthcare system (which may not be the case) there is a total of 3 253 clinicians to address the mental healthcare needs of 55 million possible service users in South Africa. If we assume a prevalence rate of 17% for

mental disorders (Kleintjes et al., 2006), then there is one mental healthcare worker for every 2 874 persons with mental illness in South Africa.

Second, South Africa's healthcare system has limited supplies of clinical equipment and medicine to treat individuals (HRW, 2011; Lund, Kleintjes, Kakuma, & Flisher, 2010; Lund et al., 2012). This would imply that service users may not receive the benchmark assessments and treatments for their condition, at times.

Third, the healthcare system is faced with financial inefficiencies (HRW, 2011). Financial constraints, however, have various repercussions for the national healthcare sector and individuals with mental disorders. Due to limited finances, healthcare facilities may not have enough funds available to cover the cost for service production for patients. Consequently, many healthcare facilities struggle, or are unable, to provide prolonged treatment (e.g., long-term institutionalisation at psychiatric institutions) for the large number of people living with, for example, schizophrenia in South Africa (HRW, 2011). Lund et al. (2012) elaborate that, in psychiatric hospitals, a shortage of beds exists to accommodate South Africa's psychiatric patient load. Lund et al. (2010) had earlier confirmed this shortage of patient accommodation in public psychiatric hospitals when they stated that less than three beds are available for every 100 000 potential service users. Consequently, after receiving initial treatment for their symptoms; patients are discharged earlier than some healthcare professionals would desire. However, Lund et al. (2012) also claim that "there is little community-based psychosocial rehabilitation" resource available for patients in South Africa (p. 403). A plausible reason for this may be attributed to the limited funding that these community-based facilities receive from government (HRW, 2011; Lund et al., 2012).

The Shift: Deinstitutionalising Individuals with Mental Disorders

Since the 1900s, the movement has shifted from long-term institutionalisation of patients, including those with schizophrenia, for observation, care, and treatment, towards an era of deinstitutionalisation (Bulger, Wandersman, & Goldman, 1993; Gutiérrez-Maldonado, Caqueo-Urízar, & Kavanagh, 2005; Pakenham, 2012; Stefan et al., 2002; Thompson & Doll, 1982). Deinstitutionalisation is defined as the process that occurs when a person, who is diagnosed with a psychiatric condition, is moved from an institution (such as a psychiatric hospital) after receiving treatment, into a community setting – for example their home (VandenBos & APA, 2015). Therefore, a deinstitutionalised individual no longer resides in a psychiatric caring facility, but rather with significant others such as family members or

friends in the community. There are many reasons for this shift, including differences in how mental disorder is perceived and understood, objections to incarceration on ideological grounds, and the perception that community-based care may be cheaper than institutional care (Pakenham, 2012; Sales 2003). It is beyond the scope of this study to assess the validity of these various views.

Thompson and Doll (1982) argue that since the 20th century many individuals with schizophrenia have no longer received prolonged treatment at institutions or psychiatric hospitals. Instead, up to 60% of patients are deinstitutionalised after receiving initial treatment for their symptoms (Lund et al., 2012; Molefi & Swartz, 2011; Ukpong, 2012).

Psychiatric facilities are designed to provide specialised care and treatment for individuals with schizophrenia. However as noted earlier, practically and financially it is not always possible for psychiatric institutions to admit individual into long-term care after their diagnosis (or while they are living with the symptoms of schizophrenia). Also, treatment centres may not have the capacity to accommodate such a large number of patients into care for a prolonged period of time. As a result, the person with schizophrenia may have to rely on other sources for support. To emphasise this, Upkong (2012) states that the majority of deinstitutionalised individuals end up living at home.

Caregiver Burden and Coping

While recovering at home, the person with schizophrenia requires a substantial amount of attention, care, and support (De Wet et al., 2015; Tan et al., 2012; Upkong, 2012). Furthermore, the caregiving task tends to be long-term orientated, due to the severity of symptoms and the impairments caused by it (APA, 2013; Sales 2003). Caregiving responsibilities may introduce a great physical and psychological burden to the carer, and affect the caregiver's relationships with others as well. This can be attributed to many factors – for example, in some cases a person with schizophrenia lacks the competence or is unable to take care of themselves (APA, 2013; Sales, 2003). As a result, the caregiver responsibility can burden carers in different ways – emotionally, physically, and socially.

Despite facing challenges in different domains of daily living, caregivers also adapt to their circumstances and develop coping strategies that assist them with the caregiving responsibility, this increasing the carer's overall quality of life. Literature shows that some of these coping strategies may be very effective. It may also be the case that there are rewards

and pleasures associated with caring for a relative with schizophrenia. Issues of caregiver burden, coping, and adjustment are explored in Chapter Two.

Research Rationale

The primary purpose of my study was to enhance the knowledge and understanding of the caregiver experience (De Wet, 2013). There exists a paucity of literature on schizophrenia caregivers' experiences in South Africa, and particularly in the Western Cape. To date, it is only the literature of Molefi and Swartz (2011) that have explored caregivers' experiences in the context of the Western Cape. While my study did share similarities of Molefi and Swartz's (2011) work, the focus of their study differed from mine. Therefore, by conducting my study, it served to narrow the gap in the current literature on caregivers of people with schizophrenia, particularly the burdens caregivers experience and the coping strategies which they utilise.

Furthermore, as this thesis will introduce in Chapter Four, the Shared Roots Project (SRP) has conducted quantitative work on caregivers of people with schizophrenia. As my study was qualitative in nature, it served to complement the work of the SRP, providing a more holistic overview of caregivers' lives, the challenges they face on a daily basis, and the manner in which they cope during difficult times.

Research Question

My study primarily aimed to address the following question:
What are the subjective experiences of caregivers of deinstitutionalised individuals with schizophrenia in the Western Cape, South Africa?

The sub-questions were:

- Which burdens are experienced by caregivers by having to care for a person with schizophrenia?
- Which coping strategies are used by caregivers of deinstitutionalised individuals with schizophrenia to deal with the caregiving task on a daily basis?

I was interested, subsidiary to the questions above, in exploring the following issues:

- How did the caregiving responsibility influence the rest of the family?
- What challenges were experienced as part of caregiving?

- How, in the opinion of the caregivers, could the challenges that carers face be reduced?
- What support did caregivers say they receive and did not receive from resources in the community (including individuals and support services), and what were their estimates of the quality and helpfulness of these?
- What positive experiences were created by the caregiver-patient relationship, if any?
- How does the caregiver perceive the patient?

Plan of this Thesis

The thesis has five chapters following Chapter One:

- Chapter Two introduces the theoretical framework from which the research can be viewed. Operational definitions of various terms, which are used throughout my thesis, are also introduced in the next chapter.
- Chapter Three explores existing literature in the schizophrenia caregiver domain. The chapter specifically focuses on the schizophrenia caregiver burden and coping strategies of carers while looking after a family member with schizophrenia.
- Chapter Four describes the methodology that guided research procedures.
- Chapter Five reports the findings of my study.
- In Chapter Six, the findings are discussed by drawing on existing literature in the field. Chapter Six concludes by exploring the strengths of and limitations to, my research and recommendations are provided for future research in the schizophrenia caregiving domain.

In summary, this chapter has laid the basic groundwork for the thesis and its rationale. In the next chapter I develop the theoretical tools for use in the study.

CHAPTER TWO

THEORETICAL FRAMEWORKS

In this chapter I present the theoretical frameworks through which the presented study was approached. My study primarily explored two different, yet related, phenomena related to schizophrenia. In relation to each of these, I draw on a theoretical research tradition. First, the study explored the caregiver's subjective experiences of caregiving burden. The phenomenon of caregiver burden was approached through and defined by the *Objective and Subjective Burden* perspective that was first proposed by Hoenig and Hamilton in 1966 (Awad & Voruganti, 2008). Second, the research also explored the coping strategies used by caregivers to deal with the caregiving task on a daily basis. This phenomenon of coping with the caregiver burden was viewed and defined by the *Transactional Model of Stress and Coping Theory* (TMSC) framework of Folkman and Lazarus (Folkman, Lazarus, Gruen, & DeLongis, 1986). Both theoretical frameworks are discussed in this chapter.

Objective and Subjective Burden of Care Perspective

Traditionally caregiver burden has been described in terms of the effects and consequences that the caring responsibility has on the caregiver (Awad & Voruganti, 2008). These comprise multiple dimensions such as, family dynamics, financial income, health, and leisure activities, to name a few (Awad & Voruganti, 2008; Maurin & Boyd, 1990). Therefore, it is not surprising that the "burden of care" (Awad & Voruganti, 2008, p. 151) has been approached from a multidimensional perspective (Sales, 2003). However, researchers are largely in agreement that these dimensions fall within two distinct components. In this regard, Awad and Voruganti (2008) argue that the framework developed by Hoenig and Hamilton is the most sensible and rounded. The first component of Hoenig and Hamilton's model is objective burden, whereas the second domain is subjective burden (Awad & Voruganti, 2008; Sales, 2003).

The Objective Burden

The objective burden represents the observable actual costs of caregiving responsibilities that can be created by caring for the person who is ill (Maurin & Boyd, 1990; Sales, 2003). Biegel, Sales, and Schulz (1991) have defined objective burden as "the time and effort

required of one person to attend to the needs of another" (p. 51). It includes all the things that the carer has to do as a result of another being ill.

According to Schene, Tessler, and Gamache (1994), objective burden is mainly experienced on four facets of caregivers' lives.

1. The first domain introduced is direct activities of care. As noted above, this includes helping the person with the mental disorder with various activities of daily living – such as administering the patient's prescribed medication for their condition and supervising the patient's actions throughout the day (Schene et al., 1994). For example, before the person became ill, they might have been able to personally maintain an adequate level of personal hygiene; however, after onset of the condition the patient possibly cannot reach the benchmark level of personal hygiene, and the caregiver has to assist and supervise them in attaining this goal.
2. The second responsibility of the caregiver may require assisting the patient with indirect tasks (Schene et al., 1994). This includes the taking over of everyday tasks that were performed by the patient prior to the onset of illness (Sales, 2003). A typical example here can be: before onset of the illness the person with the condition had the responsibility to take and collect his/her children from school, however, living with the illness disables them from doing so. Thus, a caregiver may have to fulfil this responsibility.
3. The third aspect of objective burden is to deal with the emotional needs of the person who is ill (Schene et al., 1994). For example, at times, the caregiver may have to listen to, or have to motivate, the patient when they are experiencing difficult periods as direct or indirect consequence of their diagnosis.
4. The fourth domain includes all the other effects of caregiving on many different, unspecified aspects of everyday life (Schene et al., 1994). According to Sales (2003), these effects of caregiving on other important life roles of the caregiver "may be its most pervasive and pernicious consequence" (p. 36). This can be attributed to the possibility that caregiving often includes changes in family relationships/dynamics, the caregiver's career status, social interactions, and introduces financial burden to carers, which may be stressful for them (Awad & Voruganti, 2008; Sales, 2003; Schene et al., 1994).

Maurin and Boyd's (1990) article also describes schizophrenia-specific areas of objective burden introduced to caregivers when caring for a family member. Therefore, one

can expect that some of these domains are reflected in the literature review in Chapter Three. The domains include: disturbed family relations that are caused by the disorder; financial difficulties caused by caregiving responsibilities; hampered social functioning by the patient; assistance with daily life activities; and problematic behaviour. Lefley (1996), similarly, discusses domains of burden caused by caring for a person with schizophrenia. These include: the ill family member's economic dependence; disruption of the caregiver's daily routine; and difficulties with interactions with the mental healthcare system. The latter includes confusing and embarrassing interactions with professionals. Furthermore, Lefley (1996) reveals the neglect of other family members' needs – as the caregiver's lifestyle may become too patient-focused and overlook the needs of other family members.

The Subjective Burden

On the other hand, a caregiver can also experience subjective burdens when caring for an ill relative (Awad & Voruganti, 2008; Sales, 2003). These are the stressful experiences that are created when the caregiver deals with the objective burden and its repercussions (Sales, 2003). According to Maurin and Boyd (1990), the subjective burden is the emotional cost that results when caring for someone who is ill. Five common contributors to subjective burden have been identified by Schene et al. (1994) when caring for people with a mental disorder:

1. Caregivers' experiences of distress.
2. Caregivers' experiences of stigma.
3. Carers commonly also experience a great sense of worry while providing care.
4. Caregivers' experiences of shame.
5. Caregivers may also experience guilt while providing care.

The Transactional Model of Stress and Coping

As Folkman and Lazarus (1988) point out, coping with stressful emotions has been approached from various, rather different, frameworks. First, coping mechanisms can be understood from the natural sciences or "animal" perspective (Folkman & Lazarus, 1988, p. 209). In this approach, coping with stressful emotions or life threatening events, for animals, is viewed from the "Darwinian phylogenetic perspective" (Folkman & Lazarus, 1988, p. 209). Darwin's approach accentuates that in order to cope, organisms learn behaviours that

will increase their chances of survival when they encounter danger. Here, the concept of fight or flight may, literally, serve as an example of how species may react when facing life threatening events. With regards to coping with stressful emotions, Darwin's theory suggests that humans will learn behaviours that may decrease the levels of perceived stress, which is created by the emotion.

On the other hand, coping with stressful emotions can also be understood from the ego psychology perspective. This approach defines coping as a cognitive process (Folkman & Lazarus, 1988). It states that humans develop cognitive processes, such as denial, intellectualisation, repression, and suppression to cope with the perceived stressor (Folkman & Lazarus, 1988).

Against this backdrop, Folkman and Lazarus (1988) argue that the above models do not adequately address the concept of coping with stressful emotions for two reasons. In response, the TMSC was chosen as the framework from which to view coping with the caregiving experience, as it may address the shortcomings of other coping theories, exemplified above. Additionally, as Quine and Pahl (1991) point out, the TMSC also emphasises the interaction between the person and the environment in which the stressor(s) exists.

Key Constructs in the Transactional Model of Stress and Coping

Operational definitions of the key constructs in the TMSC will be presented in this section. By doing this, I further illustrate how these constructs integrate to build this model of coping. The constructs are: stress, coping, cognitive appraisal, primary appraisal, secondary appraisal, emotion-focused coping, and problem-focused coping.

Stress. According to the TMSC, stress can be defined as the psychological state that results from a person's evaluation of their adaptation to the demands which are made of them in the particular situation (Lazarus, 1966).

Coping. The concept of coping refers to the cognitive and behavioural effort that the person makes to overcome, reduce, or endure the internal or external demands that are created by the stressful situation in their environment (Folkman, 1984).

Cognitive Appraisal. Cognitive appraisal simply means the manner in which a person interprets their experiences. However, cognitive appraisals can be primary or secondary (Folkman, 1984).

Primary Appraisal. A primary appraisal occurs when the individual judges the situation's as "irrelevant, benign-positive, or stressful" (Folkman, 1984, p. 840). When the individual judges the event as irrelevant, it means that the situation which they find themselves in poses no threat to their well-being (Folkman, 1984). Furthermore, when a person evaluates a situation as benign-positive, they feel that they have enough resources available to successfully deal with the situation. As a result, a benign-positive appraisal only leads to positive outcomes of the event. Alternatively, when a person judges an event as stressful, it implies that the situation will impose different challenges upon the person. Together with this, in stressful appraisals, the individual usually has a perception that the event will hurt them, result in significant loss or pose immediate threat to them (Folkman, 1984).

Secondary Appraisal. Secondary appraisal of an event occurs when the individual perceives the situation as stressful. "It addresses the question: *What can I do?*" to decrease the stress experienced (Folkman, 1984, p. 842). By evaluating this question, it allows the person to evaluate different coping mechanisms available to him/her to help in coping with the demands of the situation.

Emotion-focused coping. In emotion-focused coping the individual alters their emotional reaction to the stressor. Ultimately, the person changes the way they think about the stressful situation in an attempt to reduce the stress it causes (Folkman & Lazarus, 1988). It is used to control stressful situations, and may lead the person to alter the meaning of situational outcomes (Folkman, 1984). Examples of emotion-focused coping strategies are: avoidance, positive reappraisal of the situation; accepting responsibility or blame (Folkman & Lazarus, 1988).

Problem-focused coping. When an individual acts to take control of their situation in an attempt to change the scenario that causes them distress, it is termed problem-focused coping (Folkman, 1984). "Problem-focused forms of coping include aggressive interpersonal efforts to alter the situation, as well as cool, rational, deliberate efforts to problem solve" (Folkman et al., 1986, p. 572).

A Hypothetical Illustration of the Transactional Model of Stress and Coping

In the TMSC, coping comprises behavioural and cognitive efforts to control particular external and/or internal demands that are evaluated as challenging or exceeding the resources of the person (Folkman, 1984; Folkman & Lazarus, 1988).

To demonstrate how the TMSC model functions, I use a common caregiving experience as an example. Many caregivers commonly encounter a patient's aggressive and destructive behaviours while providing care for them (Molefi & Swartz, 2011; Negota & Mashegoane, 2012). According to the TMSC the caregiver will perceive and make sense of this experience in the cognitive appraisal stage. Hereafter, primary appraisal occurs – the caregiver judges the experience as irrelevant, benign-positive, or stressful. If the person evaluates the situation to be irrelevant or benign-positive, they feel that the event poses no threat to their well-being, or that they have enough resources available to effectively deal with the stressful encounter. However, when this is not the case, the caregiver then judges the event as stressful.

When the caregiver experiences the patient's aggressive and destructive behaviour as stressful, their cognitions enter the secondary appraisal stage of the TMSC. Now the caregiver considers, *what can I do to make this experience easier for me?*; consequently, the individual explores different coping strategies to deal with the patient's behaviour. Folkman (1984) adds that this may include opting for different, or a combination of, physical, emotional, social, and material assets, qualities that will assist them with coping with the demands of the challenging behaviour of the person with schizophrenia.

At this stage the coping process can either turn emotion-focused, or problem-focused. If the caregiver chooses an emotion-focused coping strategy they, for example, try to view the "silver lining" or the "bright side" of the experience (Folkman, 1984, p. 844; Folkman & Lazarus, 1980). The caregiver may think or say: *my family member may display these aggressive or destructive behaviours, but at least he/she is able to live at home with us – things could have been worse*. Having this outlook may make it easier for the caregiver to cope with their relative, as the caregiver will feel that have better control about their circumstances (Folkman, 1984).

Alternatively, or in addition, the caregiver may opt to cope with the adverse behaviour in a problem-focused manner. In this approach the caregiver may try to get the patient to change their behaviour (Folkman & Lazarus, 1980). Additionally, the caregiver can stand their ground and fight for what they believe is the acceptable patient behaviour (Folkman, 1984). However, it may sometimes be difficult to choose an effective problem-focused coping strategy for particular situations. According to Folkman (1984), the effectiveness of problem-focused coping is depended on, and mostly accompanied by emotion-focused coping strategies.

If the caregiver does not have effective emotion-focused coping mechanisms in place, this may consequently interfere with the cognitive processes required to plan effective problem-focused coping strategies. An example of this is demonstrated by Molefi and Swartz (2011) – it may, at times, be difficult for caregivers to get their relatives with schizophrenia to re-orientate their problematic behaviours into what the caregiver feels to be a socially desirable form. This challenge induces a sense of frustration for the caregiver (Molefi & Swartz, 2011). In this case, the caregiver finds it difficult to see the bright side of the encounter. Consequently, the caregiver ends up shouting at their relative with schizophrenia and the problematic situation is not effectively resolved (Molefi & Swartz, 2011). If the caregiver had stronger emotional control over the situation, it might have been easier for them to cope with the challenging behaviour.

Folkman and Lazarus (1988) further elaborate that these problem-focused and emotion-focused coping mechanisms are always changing. This can be attributed to the fact that these efforts are a function of continuous evaluation and re-evaluation of the person-environment relationship, which is also ever changing. Some of the changes in person-environment relationship also result from a person's coping strategies, which they develop to change and/or regulate the situation that is causing them distress. Lastly, Folkman and Lazarus (1988) acknowledge that people utilise both problem-focused and emotion-focused coping strategies to deal with the demands of the stressful encounter. Thus, both of these functions of coping should be considered to obtain a comprehensive understanding of what coping is.

To summarise, this chapter has outlined the theories that provide a framework from which to view caregivers' experiences of burden and coping. Caregiver burden was defined, as was caregiver coping. The next chapter explores existing literature in the schizophrenia caregiver domain. The chapter specifically focuses on the schizophrenia caregiver burden and coping strategies of carers while looking after a family member with schizophrenia.

CHAPTER THREE

LITERATURE REVIEW

Taking on the role of caregiver of a person with schizophrenia can be a life changing event. For some, adapting to the role of caregiver and the responsibility associated with it is an ongoing process (Negota & Mashegoane, 2012), and for many a lifelong struggle (Gubman & Tessler, 1987). Caregivers live with their relative who displays new, odd, and at times, distressing behaviours after the onset of a mental illness. The role of caregiver comes with many challenges that require caregivers to develop appropriate coping mechanisms to assist them through difficult times.

Against this backdrop, this chapter explores existing literature in the field of schizophrenia caregiving. Particular focus is placed on the challenges and the burdens that caregivers experience when taking on the responsibility of providing care for an individual with schizophrenia. The chapter also specifically focuses on the coping strategies that caregivers of people with schizophrenia utilise. In order to do so, I draw on literature, both in international and local contexts. However, before focusing on caregivers' experiences, the chapter explores the risk factors for schizophrenia, patients' behaviour at home, and recovery enabling factors.

Risk Factors for Schizophrenia, the Patient at Home, and Recovery Enabling Factors

It is necessary to familiarise the reader with the risk factors, the patient's behaviour, and the recovery enabling factors for two reasons. First, caregiver perceptions of patients might relate to these domains. Second, collectively these three domains related to caregivers' experiences contribute to the caregiver burden and coping.

Risk Factors for Schizophrenia

As stated earlier, much of what we know about schizophrenia and what causes it remains unknown (Stefan et al., 2002). However, in more recent years, attempts have been made to identify risk factors associated with the development of psychosis and schizophrenia (Kirmayer et al., 2015). According to Jones, Rodgers, Murray, and Marmot (1994), schizophrenia has been linked to different behavioural, social, cognitive, neurodevelopmental, and psychological abnormalities which occur during childhood or prior

to its onset. Below I refer to some of the risk factors associated with schizophrenia and other psychotic disorders in more detail.

Jones et al. (1994) argue that abnormalities in motor development, speech problems, learning difficulties, and childhood isolation during childhood should be considered as significant risk factors for adult onset of schizophrenia. Poor premorbid functioning (social, and academic functioning) from childhood to early adulthood is a well-known risk factor for schizophrenia (Cannon-Spoor, Potkin, & Wyatt, 1982). During childhood, many individuals, prior to the onset of schizophrenia, display difficulties in learning when compared with other individuals who do not develop schizophrenia later in life (Jones et al., 1994). Learning difficulties increase the probability of a person failing or dropping out of school, and according to Cornblatt et al. (2003), failure at school can be regarded as "possibly one of the earliest vulnerability signs" for developing schizophrenia (p. 636).

Environmental risk factors include trauma exposure during childhood and in adulthood. Seedat, Stein, Oosthuizen, Emsley, and Stein (2003) found that the majority of schizophrenia patients in their study reported experiences of trauma – either as victim or witness, prior to developing schizophrenia. It should also be noted that when living with schizophrenia, the disorder's effects on individuals' functioning may also induce further traumatic experiences for the individual (e.g., auditory hallucination experiences may be traumatic for some patients).

Substance abuse is also a risk factor for schizophrenia. A body of literature has established substance abuse (i.e., "alcohol, hypnotics, cannabis, amphetamines, opiates, cocaine, and hallucinogens") as risk factor for the onset of psychosis and schizophrenia (Cannon et al., 2008, p. 33). A lot of research has been done on the association between cannabis use and the development of schizophrenia (Cannon et al., 2003; D'Souza et al., 2005; Hambrecht & Häfner, 1996; Kristensen & Cadenhead, 2007; Morrison et al., 2009; Veen et al., 2004; Waldo Zuardi et al., 2012). Interestingly, cannabis can cause the onset of psychosis, but it also has antipsychotic properties.

Cannabis is a compound of Δ^9- tetrahydrocannabinol (THC), and cannabidiol (CBD). It is the THC molecule that has been shown to induce psychotic states in patients (D'Souza et al., 2005; Waldo Zuardi et al., 2012). For some high-risk individuals, exposure to THC is also associated with a conversion risk towards schizophrenia as it changes brain function over time (Cannon et al., 2008). However, CBD have been shown to have antipsychotic and anxiolytic properties (Schier et al., 2012; Waldo Zuardi et al., 2012). Therefore, one may see the value of CBD when patients use it – it can reduce the anxiety caused by their psychosis.

Kolliakou, Joseph, Ismail, Atakan, and Murray (2011) inform us of two models that explain drug use in individuals with psychosis. The first and most widely acknowledged model is the self-medication hypothesis. This theory postulates that patients use specific substances (e.g., cannabis) to relieve their disorder-related symptoms (Kolliakou et al., 2011). Interestingly, patients may abuse drugs even before the onset of their psychosis to alleviate its prodromal symptoms. Also, patients' drug use rates may peak after disorder onset (Kolliakou et al., 2011) to treat the negative symptoms (APA, 2013) of the schizophrenia. The second theory, the alleviation of dysphoria model; suggests that patients use drugs to alleviate their experiences of boredom, depression, and loneliness; experiences that are common for individuals with severe mental disorders such as schizophrenia (Kolliakou et al., 2011).

The Patient at Home

As stated in Chapter One, people with schizophrenia can display a wide and unique range of the five core symptoms of schizophrenia, as outlined in the DSM-5, while living at home (APA, 2013). As no single symptom is pathognomonic to schizophrenia (APA, 2013), patients may experience a wide range of symptoms that are shared with other mental disorders. A diagnosis with schizophrenia, therefore, introduces to the patient, a "constellation of signs and symptoms associated with impaired occupational or social functioning" (APA, 2013, p. 100). According to the DSM-5 (APA, 2013) and Fleischhacker and Stolerman (2014), at least seven symptoms or conditions that may be experienced by people with schizophrenia are outlined. Examples of these symptoms or conditions are:

1) amnesia;
2) dysphoric mood (e.g., anger outbursts, disturbed sleep patterns, lack of interest in eating or food refusal);
3) tremors;
4) cognitive impairments and poor concentration (e.g., deficits in language production, other executive functioning processes and mental processing speed);
5) affective flattening (which includes unchanged facial expressions during interactions, decreased spontaneous movements, poor eye contact with others, inappropriate affect, and lack of vocal inflections);
6) inappropriate affect (e.g., "laughing in the absence of an appropriate stimulus" (APA, 2013, p. 101); and

7) anosognosia – the inability to gain insight about being ill.

The DSM-5 explains that many of the impairments above may persist during the patient's recovery period or when they are in remission (APA, 2013). However, the repercussions thereof introduce various challenges to the patient at home. For example, patients who have impaired insight about their schizophrenia may refuse their antipsychotic medication – as they do not realise that they are ill, display poor social functioning skills, and increased aggressive behaviours (APA, 2013).

Moreover, patients may display symptoms classified as "pre-psychotic sates and prodromal symptoms" (Fleischhacker & Stolerman, 2014, p. 203). In this phase, there is an increase in the levels of nonspecific, subthreshold psychotic symptoms that causes the patient significant distress and increased functional impairment (Fleischhacker & Stolerman, 2014). Common symptoms of prodrome schizophrenia are: anxiety (e.g., specific phobias, derealisation, and social anxiety), and depression (e.g., early waking, and poor concentration) (Häfner, Riecher-Rössler, Maurer, Fätkenheuer, & Löffler, 1992).

Some patients may also live with co-morbid physical and mental disorders. Fleischhacker and Stolerman (2014) state that these co-morbid disorders can have their onset prior to the schizophrenia or as a post-psychotic condition. Examples of some co-morbid disorders associated with schizophrenia are: depressive disorders, personality disorders, drug dependence, asthma, obesity, and type 2 diabetes (Weber, Cowan, Millikan, & Niebuhr, 2009).

Recovery Enabling Factors

According to Liberman, Kopelowicz, Ventura, and Gutkind (2002) and Saunders and Byrne (2002), antipsychotic medication adherence is fundamental for recovery in schizophrenia. For most patients who comply with medication, their symptoms of schizophrenia, the related problematic behaviours, and their chances of being hospitalised are reduced. Medication adherence may therefore have a positive impact on the caregiving environment. As a result, the caregiver's quality of life may also be improved, as carers may experience less stress during caregiving (Saunders & Byrne, 2002).

Psychological interventions have been shown to facilitate the well-being of people with schizophrenia. According to Asmal et al. (2014), peer support groups and

psychoeducation can serve to modify patients' behaviour to improve their quality of life. According to Fleischhacker and Stolerman (2014), psychoeducation is a specific basic psychotherapeutic intervention for people with schizophrenia. As intervention, psychoeducation offers "systematic, structured, didactic information on the illness and its treatment, and which includes integrating emotional aspects in order to enable - patients as well as family members - to cope with the illness" (Fleischhacker & Stolerman, 2014, p. 215). In its turn, psychoeducation combined with pharmacotherapy can facilitate patients' functional outcomes (e.g., social functioning or their ability to execute daily tasks of living) and enhance family functioning when the patient lives at home (Huxley, Rendall, & Sederer, 2000; Kritzinger et al., 2011). Next, I present caregivers' experiences of burden and coping.

The Caregivers and their Experiences

Caregivers' experiences have been broadly explored internationally. In this section I draw on international literature to further illustrate common caregiver experiences – their challenges and coping mechanisms.

Caregivers' Age and Gender

Considering that schizophrenia commonly has its onset in late adolescence and during early adulthood (APA, 2013), patients living at home mostly receive care from individuals that are noticeably older than them. According to Shamsaei, Cheraghi, and Bashirian (2015), the majority of caregivers of people with schizophrenia are the parents of the patient. The reviewed literature suggests that caregivers' age can vary. In the studies reviewed, caregivers' mean ages were between 39 and 68 (Hernandez & Barrio, 2015; Martín et al., 2015; Mitsonis et al., 2012; Shamsaei et al., 2015).

Literature by Martín et al. (2015), Mitsonis et al. (2012), and Hernandez and Barrio (2015) argue that most caregivers of people with schizophrenia are female. According to Gutiérrez-Maldonado et al. (2005), and Saunders and Byrne (2002), the mothers of the person with schizophrenia usually carry "almost all responsibilities" when caring for the person at home (p. 899).

Personal Health Challenges

A body of literature has explored the physical and mental health conditions of caregivers while caring for a person with schizophrenia (Bauer, Koepke, Sterzinger, & Spiessl, 2012; Ganguly, Chadda, & Singh, 2010; Mitsonis et al., 2012). Personal health challenges can be attributed to various factors. According to Bauer et al. (2012), carers experience constant distress and feel overstrained in their caregiver role. The repercussion of this constant stress takes its toll on the caregivers' health. Caregivers' psychological well-being can also be affected by factors such as:

1) the caregiver's socio-demographic status: it has been found that younger, female, higher educated, and part-time employed caregivers experience higher levels of psychological burden (Baronet, 1999; Provencher, Perreault, St-Onge, & Rousseau, 2003; Ukpong, 2006);
2) patient characteristics: studies suggest that caring for younger, male patients induces higher levels of psychological distress in caregivers (McDonell, Short, Berry, & Dyck, 2003; Thornicroft et al., 2002). A plausible explanation for this finding may be that males, at a younger age than females, engage with substance use and thus present with behaviours that are a burden to caregivers (Veen et al., 2004);
3) the relationship between the caregiver and patient: the parents, and mostly mothers, of the patient experience greater psychological distress (Gutiérrez-Maldonado et al., 2005). Mothers are typically responsible for most of the care (e.g., helping patients with everyday tasks of living) and thus experience greater burden (Gutiérrez-Maldonado et al., 2005); and
4) clinical features of the schizophrenia: illness related behaviours (e.g., psychotic phases, and problematic behaviours) and caregivers' encounters with its symptomology have been linked with increased psychological distress experiences (Mitsonis et al., 2012).

Experiences of Caregiver Burden

As outlined in Chapter Two, caregivers can experience objective and subjective caregiver burdens while having to care for their relative at home. This section explores various caregiver burdens that have been identified in the literature.

Stigma. Stigma can be defined as "the negative social attitude attached to a characteristic of an individual that may be regarded as a mental, physical, or social

deficiency. A stigma implies social disapproval and can lead unfairly to discrimination against and exclusion of the individual" (VandenBos & APA, 2015). A body of literature has identified and explored the contribution of stigma to schizophrenia carers' experiences of caregiver burden (Hernandez & Barrio, 2015; Koschorke et al., 2014; Kung, 2003; Magana, Ramirez Garcia, Hernandez, & Cortez, 2007; Tan et al., 2012; Von Kardorff, Soltaninejad, Kamali, & Eslami Shahrbabaki, 2015). It is not only in the society at large where stigma related to caregivers and their relatives living with schizophrenia is evident, but also amongst individuals who are close to caregivers (e.g., friends and family) (Iseselo, Kajula, & Yahya-Malima, 2016). The negative attitudes result in distressing experiences (e.g., guilt and shame) for caregivers. Consequently, caregivers experience rejection from society and further isolate themselves from others. Moreover, Tan et al. (2012) found that stigma causes physical and mental health deterioration in caregivers over time. For example, Magana et al. (2007) found that caregivers who experience the effects of stigma are also more likely to develop symptoms of depression. Ultimately, stigma also reduces caregivers' ability to cope with the caregiving responsibility (Tan et al., 2012).

Dependency and disruption. Gutiérrez-Maldonado et al. (2005) found that persons with schizophrenia tend to be highly dependent on their caregivers. The dependence may be due to the patient's inability to perform various tasks of everyday living. As stated earlier, schizophrenia hampers the patient's ability in various vocational and social areas of functioning (e.g., concentration). Thus, some patients may have no other choice but to rely on their caregiver to assist them to execute certain tasks. Consequently, caregivers may need to assist patients with "most aspects of the patient's daily care, such as overseeing pharmacological treatment, ensuring that the environment is calm, controlling alcohol or other drug use, helping patients to manage their free time and dealing with everyday difficulties" (Gutiérrez-Maldonado et al., 2005, p. 902). This responsibility introduces a significant burden to schizophrenia caregivers (Gutiérrez-Maldonado et al., 2005).

A recent study by Iseselo et al. (2016) explored the different forms of disruption that may be introduced when having to care for an ill family member. First, caregiving can disrupt caregivers' daily routines. In the Iseselo et al. (2016) study, disruption of household tasks and other responsibilities were commonly voiced by caregivers. Caregivers also experienced a sense of obligation to provide care to their relative with schizophrenia. One possible reason for this is that caregivers felt that they cannot burden others with their family member who lives with schizophrenia (Iseselo et al., 2016).

Financial constraints. Caregivers commonly experience financial difficulties when having to care for a person with schizophrenia (Ganguly et al., 2010; Gutiérrez-Maldonado et al., 2005; Ohaeri, 2001; Thara, Kamath, & Kumar, 2003). Financial hardship may originate from various socio-political factors. Ohaeri (2001) argues that for caregivers who live in countries that do not provide adequate social welfare funding for patients and their caregivers, financial hardships tend to be more common. Furthermore, Thara et al. (2003) found that some caregivers face a total lack of any financial support from their life partner (e.g., husband) when caring for their relative with schizophrenia. On many occasions the caregiver is also a breadwinner for the family, and caring for their relative prevents them from meeting work commitments. Consequently, caregivers' expenses surpass that of their income when caring for a person with schizophrenia. This is because expenses increase due to the need to buy medical treatments and other resources for care. Lastly, extra expenses may occur when caregivers need to replace damaged or destroyed property due to patients' destructive behaviour (Gutiérrez-Maldonado et al., 2005).

Encountering moments of distress in the patient. Many caregivers are also burdened with having to face illness related behaviours and distressing experiences that accompany the progression of schizophrenia. Landis (1996) elaborates on how caregivers can be challenged by unexpected disruptive psychotic episodes by the patient. In severe cases, people experiencing psychosis can, at times, become violent in the caregiving environment, making it difficult to accommodate the individual at home.

Emotional burdens on caregiver. Caregivers experience feelings of distress such as, "depression, apathy, pain, bewilderment, isolation, anger, anguish, devastation, helplessness, hopelessness, denial, frustration, uncertainty, blame, and chronic sorrow; as well as acceptance and hope for the future" (Saunders & Byrne, 2002, p. 220). Similar reactions have been reported by Kate et al. (2014), Martens and Addington (2001), and Tan et al. (2005). These emotional experiences can be ascribed to the episodic nature of schizophrenia – symptoms may change unexpectedly, and the experiences that are evoked in caregivers when they witness the difficulties that the patient goes through while living with the disorder (Saunders & Byrne, 2002).

New activities for caregivers. Kate et al. (2014) describes the demanding task of caring for an individual with schizophrenia. Caregivers are responsible for staying with the individual with schizophrenia around the clock, especially at times when they may be suicidal or irritable or need treatment. Furthermore, carers are expected to engage in meaningful patient-activities, as noted earlier by Gutiérrez-Maldonado et al., 2005 (e.g., supervising

patients' antipsychotic medication use). These responsibilities may become extensive and too much for one person to handle. Consequently, caregivers might be unable to engage in social interactions with family or friends to the level that they desire.

Difficulties associated with mental healthcare services. As it will become clear later in this chapter, mental healthcare services play a fundamental role in caregiver coping. Overall, healthcare services that function to improve the patient and caregivers' quality of life offer carers hope for the future and support during difficult times. However, Saunders and Byrne (2002) found that some caregivers of people with schizophrenia have a need for more collaborative interactions with mental healthcare professionals. Caregivers have the desire to be actively involved in the treatment of their relative. Furthermore, caregivers also experienced that, at times, clinicians did not consider their cases to be serious or did not treat them with dignity.

Coping

Religion and spirituality. A body of literature has explored the role of religion and spirituality in coping with the demands of caregiving (Ganguly et al., 2010; Hernandez & Barrio, 2015; Huang, Sun, Yen, & Fu, 2008; Iseselo et al., 2016; Rammohan, Rao, & Subbakrishna, 2002). According to Bauer et al. (2012), caregivers' religion and their search for understanding the disorder facilitated their sense of coping; possibly caregivers also find meaning regarding the schizophrenia through religion. Religion is a core coping mechanism for caregivers (Huang et al., 2008). Ganguly et al. (2010) argue that carers found comfort when they had faith in a God. Caregivers believed that if they take the responsibility of helping their relative with schizophrenia God will help them and carry some of the caregiving responsibilities, and this will make their life easier (Ganguly et al., 2010). Additionally, caregivers believe that if they are committed to religious acts, such as fasting, God will free them from their circumstances. Ultimately, it allows them to hope for a better life and hassle-free future (Ganguly et al., 2010).

Emotional reactions that facilitate coping. Different emotion-focused coping strategies have been identified in literature. Acceptance as a cognitive-emotional process is one of the strategies that ease caregivers' experiences of burden (Huang et al., 2008; Iseselo et al., 2016). Huang et al. (2008) explain that caregivers, who battle to accept their relative's schizophrenia or their personal status quo, find it difficult to cope and experience greater

burden. Dyck, Short, and Vitaliano (1999) and Hassan, Mohamed, Elnaser, and Sayed (2011) identified that caregivers utilised avoidance as another coping strategy. When avoiding stressful experiences, caregivers may not experience emotional reactions as intensely as they normally would. When caregivers avoid challenging experiences they may use this opportunity to seek other resources for support and coping (e.g., approaching others for social support). A study by Shibre et al. (2003) identified that caregivers draw on their emotional strength as a coping mechanism. When caregivers rely on their emotional strength, they are able to cope more effectively during difficult times. Moreover, religious practises are the leading mechanism which caregivers utilise to build their emotional strength (Shibre et al., 2003).

Making sense of schizophrenia and self-education. In order to cope, some caregivers attempt to make sense of a range of experiences connected to schizophrenia and caregiving. In the Huang et al. (2008) study, caregivers engaged in activities to increase their knowledge about the disorder (e.g., reading books on schizophrenia). Consequently, caregivers are empowered by an understanding of their experiences and this may improve their coping skills.

Psychoeducation and support groups for caregivers. As stated earlier in this chapter, psychoeducation is one of the fundamental recovery enabling agents for people who live with schizophrenia (Asmal et al., 2014; Fleischhacker & Stolerman, 2014). However, a body of literature has also explored the effects of psychoeducational interventions on caregivers of people with schizophrenia (Birchwood & Smith, 1987; Cassidy, Hill, & O'Callaghan, 2001; Hassan et al., 2011; Lim & Ahn, 2003; Sunanda, Ramesh, & Victoria, 2013). Educational interventions can increase the acquisition and retention of knowledge about schizophrenia, across all knowledge areas (Birchwood & Smith, 1987). For example, caregivers can gain knowledge about schizophrenia, its symptoms, and treatment interventions, which may equip them to manage distressing times better. Limited knowledge about schizophrenia may lead to the acquisition of negative coping strategies. Negative coping strategies are mechanisms that induce additional burdens rather than alleviate caregivers of the stressors they experience (e.g., engaging in negative self-talk or engaging in substance abuse). Consequently, caregivers may experience increased levels of burden (Lim & Ahn, 2003). Sunanda et al. (2013) summarise the coping potential that psychoeducation can offer caregivers of people with schizophrenia:

> Psycho-education on schizophrenia reduces the burden level among caregivers' of patients with schizophrenia. Therefore the psycho-education targeting the caregivers

> of patients with schizophrenia should results in successful treatment, regular follow-ups and rehabilitation of their patients and also helps them to control and manages their stress and burnout (p. 126).

Interestingly, psychoeducation may not always alleviate caregivers' experiences of burden (McDonell et al., 2003). Several factors may influence the effectiveness of psychoeducation. First, caregivers who have been caring for patients for a prolonged period could have adapted to the burdens of caregiving and may therefore be less likely to benefit from psychoeducation. Second, it may be the case that the patient's behaviour and symptomology had changed for the better over time, and therefore, caregivers experience fewer burdens than before.

Additionally, peer support groups for caregivers can alleviate caregivers' perceived levels of burden (Chien & Thompson, 2013; Iseselo et al., 2016; Yesufu-Udechuku et al., 2015). Peer support groups can offer the opportunity for caregivers to address their bio-psycho-social needs in a self-help manner. It has been found that caregivers who participate in support groups in the long term perceive less psychological burden when compared to others who do not access psychological resources (Chien & Thompson, 2013). One plausible reason for this reduction in perceived stress is that in support groups, caregivers form social interactions with their peers and experience a sense of social support. According to Iseselo et al. (2016), caregivers are in need of social support to vent their emotional distress.

Social support. "Caregivers of people with mental illness need, in particular, emotional relief and support from family and social environment. Caregivers want to talk about their fears, worries, doubts, and feelings of sadness and guilt and want their burden to be eased" (Bauer et al., 2012, p. 932). According to Huang et al. (2008) and Saunders and Byrne (2002), caregivers of people with schizophrenia value the support from and relationships with their family and friends. Particularly, family support offers a great support for caregivers while caring for their relative (e.g., assisting with ideas to provide care) or during difficult times (e.g., sharing in the pain and having empathy with the caregiver's and patient's distressing experiences).

Professional services. The Saunders and Byrne (2002) study also stressed the value that mental healthcare services offer to both patient and their caregivers. When caregivers receive assistance with care for their relative with schizophrenia from clinicians, it offers them hope, support, encouragement and the strength to carry on during difficult times. In essence, caregivers realise that they are not alone in their role and that during difficult times

they are able to rely on specialists to assist them and facilitate the well-being of both their lives and that of the patient.

Positive experiences while being a caregiver. Some caregivers also experience their role as rewarding (Bauer et al., 2012, p. 932). According to Bauer et al. (2012), caregivers reported that caregiving increased their self-confidence, helped them realise their inner strength and made them more mature. Caregivers also reported that they had become more aware of their own needs – an example may be caregivers who acted to look after their own health needs. However, Hassan et al. (2011) found that caregivers use positive reappraisal of their situation as coping mechanism. When carers thought positively about their circumstances, it increased their self-esteem and made them feel more optimistic about life (Capara & Steca, 2005; McCann, Lubman, & Clark, 2009; Zauszniewski, Bekhet, & Suresky, 2009). Positive experiences related to caregiving may further form the platform for closer and deeper relationships between caregivers and the patient. However, McCann et al. (2009) note that it is fundamental that both patients and caregivers display hope towards the patient's recovery and the future.

Schizophrenia Caregiving in South Africa

There is a paucity of literature that specifically investigates the experiences of caregivers in the South African context. Studies, such as those of Kotze, van Delft, and Roos (2010), Mhaule and Ntswane-Lebang (2009), Molefi and Swartz (2011), and Negota and Mashegoane (2012) inform us about caregivers' experiences in various parts of South Africa. More recently, it is only the Molefi and Swartz (2011) study that was conducted in the Western Cape that could inform us about caregivers' experiences in this province. This section draws on the above-mentioned studies and on other local literature, to form the basis of experiences that were to be expected when conducting my study.

Kotze et al. (2010) conducted qualitative work on a relatively large sample of caregivers. Fifty caregivers of patients with schizophrenia participated and identified at least three caregiver experiences. First, caregivers experience a lack of knowledge about schizophrenia and disorder-related topics. Motlana, Sokudela, Moraka, Roos, and Snyman (2004) similarly found that information about schizophrenia was disseminated ineffectively between healthcare professionals and caregivers. Motlana et al. (2004) found that the majority of participants in their study did not know what schizophrenia is. Second, caregivers experienced a sense of responsibility regarding making decisions on behalf of the

patient. Third, that there exists a need for psychosocial care programmes for caregivers of people with schizophrenia (Kotze et al., 2010). A possible reason for the latter is because caregivers play a fundamental role in the care of patients and being closely involved with the patient's illness may take its toll on the caregiver's psychosocial functioning. Consequently, up to 94% of caregivers may need social support after taking on this caregiving responsibility (Kotze et al. 2010; Mhaule & Ntswane-Lebang, 2009). Possible interventions at this level may be support or psychoeducational groups for caregivers (Kritzinger et al., 2011). However, when designing these coping resources, professionals should remember that an individual's culture, religion, and level of education shape their outlook about schizophrenia and related experiences. Thus, interventions should be sensitive to the caregiver's point of reference to increase its effectiveness (Asmal, Mall, Kritzinger, Chiliza, Emsley, & Swartz, 2011; Motlana et al., 2004).

Mhaule and Ntswane-Lebang (2009) aimed at investigating English and SiSwati speaking schizophrenia caregivers' experiences in the Mpumalanga Province and encouraged participants to voice their needs when providing care. Interestingly, all caregivers were female in Mhaule and Ntswane-Lebang's (2009) research. From this research it is possible to gain an understanding of the burdens that caregivers might experience. Mhaule and Ntswane-Lebang (2009) found that caring for a person with schizophrenia is not always an easy task. While facing this, at times, challenging responsibility, caregivers may experience emotions of anger, distress, fear, frustration, guilt, sadness, and worry. Moreover, caregivers are burdened with the patient's non-adherence to medication, poor hygiene maintenance, problematic behaviour (e.g., destructing carers' property), and stigmatisation by others in the community. Kritzinger et al. (2011) identified a connection between stigmatisation and non-adherence to medication. Stigmatisation, together with the side effects of the antipsychotic medication, increased the rates of non-adherence in patients' medication use. It has also been found that non-adherence to medication increases the patient's chances of a relapse. When patients display schizophrenia symptoms they may appear odd or different to others in the community which in turn might create a platform for further stigmatisation from persons who lack understanding about the disorder. Furthermore, Negota and Mashegoane (2012) state that stigmatisation can lead to caregivers socially isolating themselves.

In their study, Negota and Mashegoane (2012) explored the experiences of eight mothers of children with schizophrenia in a rural setting. The average age for caregivers was 51 years, while the average age of patients were 21 years. In accordance with Mhaule and Ntswane-Lebang's (2009) study, Negota and Mashegoane (2012) confirmed caregivers'

experiences of anger, fear, and frustration – however, specifying that these emotions are experienced at the moment of the patient's diagnosis. These emotions can result from caregivers' lack of knowledge on how to handle the situation. Caregivers further experienced a sense of loss – they felt that they had lost their idealised child and the relative they used to know before the patient became ill. Furthermore, caregivers are burdened by patients' violent and aggressive behaviour. Caregivers commonly reacted with a sense of fear for the patient, as carers are concerned about their personal safety (Negota & Mashegoane, 2012).

Additionally, hospitalisation of the person with schizophrenia and having support from one's spouse were significant coping agents identified by caregivers. However, in South Africa, where many caregivers report high rates of unemployment and poverty, hospitalisation of patients cannot be afforded by all. Moreover, caregivers have reported that the grant that they receive for caring for a person with a disability is not sufficient to fund their caregiving-related and other life expenses (Negota & Mashegoane, 2012).

Molefi and Swartz (2011) investigated 10 families' experiences of caring for an individual with schizophrenia. By exploring family members' experiences, Molefi and Swartz (2011) confirmed the emotional burden that caregivers face. According to Molefi and Swartz (2011), caregivers find it difficult to live with patients who isolate themselves from interactions at home. As a result, caregivers experience a sense of frustration which leads to verbally aggressive behaviour towards their relative with schizophrenia. Additionally, like other caregivers in the Negota and Mashegoane (2012) study, carers had to face destructive patient behaviour at home.

Outside the immediate caregiving environment, caregivers confirmed stigmatisation from community members related to the schizophrenia. Consequently, caregivers found it difficult to disclose aspects of their relative's schizophrenia to others (e.g., extended family members or colleagues) that do not interact in the caregiving space on a regular basis. Molefi and Swartz (2011) further identified the poor relations existing between caregivers and healthcare professionals. This may introduce its own challenges. For example, a communication gap between these parties may inevitably lead to healthcare professionals missing key information conveyed by the caregivers or patients, and vice versa. It is suggested that caregivers should be better included in and informed about the treatment plan for their relative.

To summarise, it appears that to date few studies have been conducted that specifically explore caregivers' experiences of burden in the care of patients with schizophrenia in the South African context. The reviewed literature, nevertheless, informs us

about common challenges and coping agents that caregivers reported in South Africa. In terms of challenges, caregivers first experience multiple emotions at diagnosis and throughout the caregiving task. The fact that more than one study identified caregivers' lack of understanding of schizophrenia may suggest that for many caregivers, uncertainties about their experiences can manifest as soon as their relative is diagnosed. Literature also suggests that healthcare professionals can act to alleviate caregivers from this burden.

Throughout caregiving, caregivers are faced with numerous experiences that are caused by the patient, other family members, or members of the community. First, caregivers encounter various problematic behaviours from or between them and their relative. Second, caregivers generally realised the importance of antipsychotic treatment adherence and the positive consequences thereof. Third, stigmatisation appeared to be ever present in caregivers' perceptions.

On the coping spectrum, local literature identified the value that social support resource and professional support structures can offer to caregivers' lives. However, it is important that mental healthcare coping resources are moulded to the needs and context of the caregiver to enhance their effectiveness.

This chapter has provided the platform for understanding caregivers' experiences globally. It has introduced us to experiences that might be shared by others who have the same role as caregiver, when conducting my study. Next, the thesis discusses the methodology that guided my research.

CHAPTER FOUR

METHODOLOGY

This chapter will focus on the methodology that was followed in conducting my study. It is divided into the following sub-sections: the research design and approach, the research setting, sampling, data collection, the data analysis, and, ethical considerations.

Research Design and Approach

My study formed part of a broader project which was large scale and largely quantitative in nature. For this sub-study, I utilised a qualitative approach, as it was the best suited methodology to address my research question(s).

Qualitative research designs commonly use words rather than numbers to investigate and explore social phenomena (Bless, Higson-Smith, & Sithole, 2013). Qualitative research generally investigates fewer cases compared to quantitative research methodologies, but delves more deeply into the person's story and their explanation of social phenomena (Baker & Edwards, 2012). In this way, qualitative methods aim to create an understanding of *how* individuals subjectively perceive the world around them, and *why* they attribute certain stories to their experiences (Baker & Edwards, 2012; Bless et al., 2013).

As stated in Chapter One, the aims of my study were two-fold. First, I aimed at investigating caregivers' experiences of caregiver burden. Second, I aimed at exploring the coping mechanisms that caregivers use. The use of qualitative research methodologies allowed me to obtain an in-depth story, the *how* and *why*, of caregivers' unique yet universal experiences of being a caregiver, and providing a rich contextualised understanding of caregiver experiences.

Furthermore, my project was exploratory in nature. Exploratory research is usually carried out when there is insufficient research available on a particular subject matter (VandenBos & APA, 2015). An exploratory approach was particularly suited in this case, as there is a paucity of literature which investigates schizophrenia-caregivers' experiences. To my knowledge only one other study, by Molefi and Swartz (2011), has explored the experiences of caregivers of people living with schizophrenia in the Western Cape of South Africa's context.

My project was influenced by the phenomenological approach to research (Creswell, 1998). In this approach the aim is for the researcher to obtain an understanding of how

individuals (in this case the caregivers who participated in the study) experience the world within their particular contexts at a specific moment in time. In this way, phenomenological work sets aside that "which we (think) we already know about" the world and people's experiences (Willig, 2013, p. 251). Rather than trying to explain social phenomena in an abstract nature, a phenomenological study focuses on the perceiver's conscious explanation, engagement, and understanding of the world around them (Willig, 2013). Thus, my study investigated the individual's *lived experiences* of being a caregiver of a person with schizophrenia who is deinstitutionalised – the goal was to obtain knowledge of the caregiver's content of consciousness and his/her experiences of the caregiving responsibility.

> Kvale (1996) summarises the phenomenological approach in the following way: Phenomenology is interested in elucidating both that which appears and the manner in which it appears. It studies the subjects' perspectives of their world; attempts to describe in detail the content and structure of the subjects' consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings. (p. 53)

The Research Setting

My study was conducted at the Schizophrenia Research Unit (SRU), which is part of the Department of Psychiatry, Stellenbosch University. The SRU is situated on the premises of Stikland Psychiatric Hospital (SPH), however it is not affiliated with the hospital. All data collection took place on-site at SRU where I was provided with a consultation room. I received permission to contact patients (and their caregivers) who had previously participated in a schizophrenia out-patient study, the Shared Roots Project (SRP), that was taking place at the SRU.

Stikland Psychiatric Hospital

While my study was not in any way associated with SPH, it was conducted in a research unit on the hospital grounds. It is necessary to familiarise the reader with the hospital, because many caregivers' accounts may refer to SPH when reporting the results of my study (in Chapter Five). I also refer to SPH in my self-reflection of this study later in this chapter.

Stikland is a public government funded psychiatric hospital that provides secondary and tertiary level mental healthcare to individuals (Stikland Hospital, n.d.). Here, multi-

professional teams consisting of, but not limited to, nursing personnel, occupational therapists, pharmacists, psychiatrists, psychologists and social workers work to improve the holistic well-being of institutionalised and deinstitutionalised service users (Stikland Hospital, n.d.).

The hospital is situated in Bellville, in the Northern suburbs of Cape Town. Stikland Hospital's official webpage reports that the hospital serves a population of over 1.4 million people (Stikland Hospital, n.d.). The catchment areas for Stikland are: the rural regions of the West Coast and the Winelands, and various sub-districts of the Cape Town Metropole.

The Shared Roots Project

The SRP is a quantitative project that was, at the time of my study, investigating the molecular and brain circuitry aetiology of two categories of chronic non-communicable diseases. One of the categories is neuropsychiatric disorders (NPDs). Three NPDs were under investigation – Parkinson's disease (PD), Post Traumatic Stress Disorder (PTSD), and Schizophrenia. The second category of chronic conditions was cardiovascular disease (CVD).

The SRP aimed at finding common pathogenic signatures of NPDs in the context of modifiable risk factors for CVD and diabetes. The SRP research team seeks to discover genomic, neural, cellular and environmental aspects that are common risk factors for NPDs, CVD and diabetes that contribute to the co-morbidity, symptom severity, and treatment outcomes of these three disorders.

A sub-study of the SRP focuses on the long-term clinical and functional outcomes of first-episode schizophrenia spectrum disorders. In addition, the sub-study focuses on the impact of caregiving on the family members of patients living with schizophrenia. To generate this information, the sub-study employed a quantitative data collection tool, namely the Experiences of caregiving (ECI) scale. In brief, the ECI is a 66-item, self-report, instrument that provides a "comprehensive description of the caregiving experience with a relative with serious mental illness" (Jorge, & Chaves, 2012, p. 274).

My qualitative work complements that of the SRP sub-study. The in-depth rich data emerging from my study, which I present in the next chapter, was collected to enable a more holistic understanding of caregivers' experiences. According to Pope and Mays (1995), there are at least three ways in which qualitative work can supplement quantitative research. First, qualitative work, when it precedes quantitative research, can provide a description and

understanding of the event or phenomenon which is being investigated. An example of this may be when participants are unable to understand certain professional terms that are used for psycho-social phenomena. Qualitative strategies can establish which terms would be most suited to use for data collection in the quantitative work to follow. Second, qualitative work can supplement quantitative research when it serves to validate the quantitative findings, or vice versa. Third, qualitative research can complement quantitative studies when the narratives obtained from the former enable researchers to explore complex phenomena or areas not amenable to quantitative research. To support this, Pope and Mays (1995) argue that "qualitative work can reach aspects of complex behaviours, attitudes, and interactions which quantitative methods cannot" (p. 45).

Sampling

Participants were recruited by means of convenience sampling from the population of caregivers who were caring for a person with schizophrenia who was, or had been, participating in the SRP. This sampling strategy is characterised by a method of selection of participants which is neither random, nor systematic. A common reason for this, as in this study, is that the participant sample is selected by the researcher based on their availability (VandenBos & APA, 2015). The SRP study coordinator provided me with a list of 19 potential caregivers to approach for my research. This method may introduce sampling bias – "a systematic and directional error involved in the choice of units, cases, or participants from a larger group for study" (VandenBos & APA, 2015, p. 932). Subsequently therefore, it is important to mention that data obtained from this recruitment strategy may not be an accurate representation of the larger population of schizophrenia caregivers, in for example, other communities (VandenBos & APA, 2015).

Moreover, convenience sampling is a form of non-probabilistic sampling (Bless et al., 2013; Guest, Bunce, & Johnson, 2006). In this form of sampling, the probability of each element as it occurs in the population which the sample is drawn from, is unknown (Bless et al., 2013). Guest et al. (2006) argue that ideally all research should utilise probabilistic sampling methods. The reason for this is that in probability sampling approaches, each element as it occurs in the population which the sample is drawn from can be calculated (Bless et al., 2013). Furthermore, in probability sampling methods all individuals in the population have equal chances of being selected as members of the study sample (Bless et al., 2013). However, as Guest et al. (2006) explain, it is almost impossible to utilise probability

sampling methods with hard-to-reach populations, as it was the case with the participants in my study. Furthermore, as Guest et al. (2006) point out, when research is not focused on statistical generalisability, such as in the case of qualitative research, researchers can opt for non-probabilistic methods instead.

Considering that the participants of my study were a vulnerable population, I decided on specific cases suited for the study sample. After familiarising myself with the literature in the field of schizophrenia caregiver burden and coping, the strategy was to select participants who I judged to be the most common in the population under investigation, and especially in the South African context. Therefore, the inclusion criteria for my study were as follows:

1. the caregiver is older than 18 years of age, and caring for a deinstitutionalised individual who is older than 18 years of age;
2. the caregiver should be a family member, or the primary carer, of the person with schizophrenia;
3. the individual with schizophrenia was deinstitutionalised after his/her first episode of schizophrenia; and
4. the caregiver is fluent in either Afrikaans or English.

Despite the fact that I had a list of 19 possible caregivers to use for recruitment, the sample size of my study could not have been estimated in advance, as data were collected until data saturation was reached. Data saturation is reached once the addition of further information adds no novel findings to the existing data (Bless et al., 2013; Guest et al., 2006). It is in the nature of data saturation that the specific number of cases needed to reach saturation cannot be predicted in advance. Guidelines in existing literature of *how many* interviews are needed to ensure data saturation are unclear (Guest et al., 2006). This is because each study is unique in its own way, and the point of data saturation cannot be generalised in the field of qualitative research (Baker & Edwards, 2012). After data saturation is reached, the findings become repetitive and there is no need to continue with the sampling process and data collection (Guest et al., 2006).

According to Creswell (1998), when qualitative studies are phenomenological in nature – as was the case with my research – between five and 25 interviews are generally sufficient for data saturation. In exploring actual practices concerning data saturation in sixty qualitative studies in the health field, Guest et al. (2006) found a general pattern that the initial six interviews are crucial in data collection, as most of the findings appear in these interviews (Guest et al., 2006). The results, however, further expand notably until the 12th

interview. According to Guest et al. (2006), 88% of research findings may be explained after 12 interviews have been conducted. This implies that the next 48 interviews (interviews number 13-60) generate the last 12% of data that contribute to complete data saturation.

My study met the guidelines for data saturation as set by Creswell (1998). Furthermore, in acknowledging Guest et al.'s (2006) argument, I conducted semi-structured interviews with 13 participants[1].

Recruitment Strategy

After I was granted access to the SRP's participant database, the person living with schizophrenia and his/her caregiver's contact details were made available to me. Thereafter, I contacted potential participants via telephone. During this communication, I asked the caregivers if they were willing and available to join my study. Furthermore, I also informed caregivers about the nature of my study – what it entailed, and their responsibilities if they were to agree to participate. Furthermore, I requested that the person with schizophrenia, who was being cared for, accompany the caregiver to the first meeting, as the patient was to complete documentation for ethical procedures (these ethical aspects are explained later in this chapter). Following this, participants who agreed to participate were invited to the first data collection meeting at a mutually convenient time for all parties involved.

Data Collection

During the first meeting, data were collected by means of a semi-structured interview. As only the semi-structured interview data were considered for analysis in this study, the text in this section consequently only discusses this method of collecting information. Following this, I describe theoretical aspects and the execution of the pilot interview that I conducted before my formal study commenced. This section will continue with describing the happenings on the day of the first data collection appointment(s). Thereafter, I elaborate on a number of techniques that I utilised to facilitate the interviews and to enhance the data collection process. Lastly, this section concludes by discussing factors that I have addressed to improve the trustworthiness of my study.

[1] There was a subsequent photovoice component to this study which does not form part of this thesis and which will be reported on elsewhere.

The Semi-structured Interview

There are many different ways of collecting information directly from people. One of the approaches is by means of an interview (Bless et al., 2013). According to Hugh-Jones (2011), in qualitative research the interview is one of the most powerful ways of obtaining knowledge about others' experiences. Moreover, it is also one of the most legitimate and respected ways of generating information and an understanding of people and their experiences (Hugh-Jones, 2011). One of the key requirements for an interview is that there is direct personal interaction between the person collecting the information (the interviewer) and the person producing the information (the interviewee) (Bless et al., 2013). However, many forms of interviewing exist, each differing in respective ways.

One form of interviewing is by means of a structured interview (Bless et al., 2013; Sommer & Sommer, 1980). This approach utilises questions developed in advance of the interview, which the researcher poses to the interviewee. This process is very rigid, and the same questions are asked of each interviewee in the same order (Hugh-Jones, 2011). In this way, the structure allows the researcher to collect information in a consistent manner from one situation to the next (Sommer & Sommer, 1980). However, Hugh-Jones (2011) points out that this form of interviewing is not best suited to qualitative research, where the researcher is "more concerned with an evocative communication of people's life experiences, activities, emotions and identities" (p. 78). As a result, in qualitative research, an interview with less structure is preferred, which allows the "interviewees opportunity to expand their answers and give complex accounts of their experiences" (Hugh-Jones, 2011, p. 78). A form of such a less-structured interview is a semi-structured interview (Bless et al., 2013; Hugh-Jones, 2011; Sommer & Sommer, 1980).

As noted, a semi-structured interview allows the interviewer to obtain a more comprehensive account of interviewees' experiences. Due to this, utilising a semi-structured interview approach was ideal for my study. This form of interviewing is founded upon three key principals (Hugh-Jones, 2011), and I shall explain what these are and how I applied them.

1. A semi-structured interview has clear theoretical underpinnings (Hugh-Jones, 2011). This implies that it has a theory-guided view of the interviewee, and the phenomenon or experiences under investigation. To address this in my study, I have viewed the schizophrenia caregiver burden and the coping strategies in this regard, from the different theoretical perspectives suited to them, as discussed in Chapter Two of this thesis. Furthermore, I have reviewed local and international literature that deals with

the respective phenomena and population under investigation, as earlier explored in Chapter Three of this thesis.

2. A semi-structured interview is exploratory in nature and is concerned with the interviewee's subjective accounts of the topic under investigation (Hugh-Jones, 2011). Due to this, it is not expected that all of the issues, or ways of experiencing phenomena, are known to the interviewer in advance. Also, this approach is not concerned with "fact-finding or getting verifiable accounts" of the topic (Hugh-Jones, 2011, p. 79). Rather, it acknowledges the fact that human experiences can be diverse and unique – utilising a semi-structured interview can explore this and educate others about important aspects of human behaviour (Hugh-Jones, 2011). To address this principle, I developed an interview schedule that relied on open-ended questions. This approach allowed the interviewee to explore topics and to generate complex narratives for investigation (Sommer & Sommer, 1980). Furthermore, I also allowed new ideas to be introduced as a result of what the caregivers said (Bless et al., 2013).
3. While the interviewer may have a general idea in mind and may want to ask specific questions, there is, however, no predetermined order or specific wording to questions asked during the interview – as is the case in the structured interview (Sommer & Sommer, 1980). To increase the chances of meeting this quality of interviewing, I used a number of qualitative interviewing techniques to facilitate the interview process to ensure that I collected rich narratives from the caregivers (these techniques will be described later in this section).

A semi-structured interview may be an effective way of generating and collecting information; however, it also has shortcomings that cannot be ignored (Hardon, Hodgkin, & Fresle, 2004). One of the shortcomings, and applicable to my study, is that the researcher needs to know something of the local culture to capture the interviewees' real meaning related to the narratives (Hardon et al., 2004). I grew up in South Africa and am aware of the country's diverse population. I further conducted the literature review in Chapter Three of this thesis. This may have provided me with some knowledge of the local culture. However, I cannot claim that I am completely familiar with the cultural context of all the participants in my study. I have to allow for the possibility that I introduced bias into the interview or was not attentive to cultural nuances. Furthermore, while the interview is one of the most popular and effective data collection techniques in qualitative research; another critique against it is raised by Hammersley and Gomm (2008) when they argue:

> what people say in an interview will indeed be shaped, to some degree, by the questions they are asked; the conventions about what can be spoken about; … by what they think the interviewer wants; by what they believe he/she would approve or disapprove of (p. 100).

This comment may suggest that the interviewee will only disclose information which they feel comfortable sharing with the researcher. Also, the interviewee can only reveal their perceptions of the event, topic or experience being discussed. Furthermore, as suggested by the above quotation in Hammersley and Gomm (2008), the interviewee's responses might be inconsistent with their reality, providing, instead, socially desirable narratives.

Nevertheless, I attempted to avoid bias in a number of ways. I shall elaborate on these next:

1. I created an interview schedule (please see Appendix A) with open-ended questions. Open-ended questions are characterised by the fact that they start with words such as, why, what, where, and how; wording questions in this manner allows the interviewee to explore topics and to generate complex narratives for investigation (Sommer & Sommer, 1980).
2. Additionally, the interviews explored both, negative and positive aspects of the caregiver experience and all the narratives were reported in the results.

The Pilot Interview

Before data collection from the caregivers formally started, I conducted a pilot interview. A pilot interview can be best explained as a trial run of the interview that a researcher is planning to conduct in his/her formal study (Wood, Giles, & Percy, 2012). It is important to note that a pilot interview does not contribute to the findings of a formal study. Instead, a pilot interview contributes to the planning, practising, and improvement of the interview procedure that a researcher plans to follow (Sommer & Sommer, 1980; Wood et al., 2012). Essentially, the researcher practices the interview and his/her interviewing skills during this session. Additionally, after the conclusion of a pilot interview, the researcher may choose to make slight changes to the interview schedule and the way to approaching the interviewing process.

Pilot interviews are usually conducted with individuals who are familiar with the researcher, or with individuals whose information will not be used for data analysis in a

presented study (Wood et al., 2012). Hence, conducting a pilot interview(s) with my brother allowed me to practice my interviewing skills and interview schedule before the study commenced. I specifically decided on my brother as candidate for two reasons. The first reason was that he was living with me at that stage and was readily available to be interviewed. The second reason was that my brother also holds an Honours Degree in Psychology and he is a registered counsellor in the field of substance use disorders. As a result, I believed that he would be able to point out aspects of my interviewing skill that could be improved on. My brother also has knowledge of schizophrenia as a mental disorder and could manufacture more condition-related information for the mock interview.

The pilot interview ultimately allowed me to become comfortable and familiar with the interview schedule and in interacting with the interviewee. To follow, I present the issues that arose during the pilot interview, and how I addressed each before formal interviews initiated with the participants in this study.

The issues that arouse during the pilot semi-structured interview. After conducting the pilot interview, I asked my brother for feedback on the session. My brother pointed out two positive aspects of my interviewing style that facilitated him in sharing narratives during the interaction. The first quality was that I gently explained questions that were difficult or unclear to him. My brother felt that there were stages where he was "battling to understand" my responses or follow-up questions, but that I gently went about re-explaining or rephrasing these to him. The second positive remark that my brother made after the interview was that my body language was open to, and accepting towards the story that he was producing. He said that this quality allowed him to see the interview as a "safe space" where he could openly share the content at mind.

My brother also identified two aspects of my interviewing approach which he felt were obstructing him from producing optimal narratives. He told me that I did not respect silences sufficiently, and that I rushed to fill any spaces between talk. Second, what I thought of as encouraging gestures, such as saying "hmmm" to indicate that I was listening intently, were experienced as intrusive by him.

My brother felt that there were stages where I disrupted his "line of thought" when I filled the silent moments with speech. He advised me to allow a 5-10 second space for silence between communications after the participant has spoken. Furthermore, my brother noted that I frequently made an "hmmm" sound while he was communicating to me. This "puzzled" my brother, as at times he wondered why I was making this sound. He afterwards asked: "does the hmmm mean that you are hearing my story?"; "does it mean you are getting

bored with what's being told?"; or "are you stunned by the tale that I am fabricating to practice the interview with you?"

In conclusion, I regarded this feedback as helpful to increasing my chances of conducting a successful semi-structured interview during my study. On the one hand, if I were to replicate the positive aspects that my brother experienced during the pilot interview with participants, this could potentially facilitate carers to share detail rich information with me. On the other hand, if I were to repeat the negative aspects with participants that had arisen for my brother during the pilot interview, it could result in restricting caregivers' sharing of detailed rich information with me. Therefore, I took note of his feedback and consciously reminded myself during the formal interviews to draw on the positive qualities and to avoid introducing the negative aspects again.

Finally, it is important to mention that no changes were made to the interview schedule after the pilot study was conducted. However, in the formal study I did, at times, not ask questions in the chronological outline as found in Appendix A. I felt that it was more suited to follow the caregiver's narrative thread – to comment or ask follow-up questions in the moment, and thereafter return to the interview schedule to ask the next question on this interview program.

On the day of the Interviews

Each interview was, in terms of the nature of the research design, unique. Here I summarise some common features across a diverse set of interviews.

Starting the first appointment: the welcoming and briefing of caregivers. The first time I met caregivers in person was at the first appointment, which marked the semi-structured interviews. Participants and the patient being cared for were welcomed with refreshments in a room at SRU.

Wood et al. (2012) warn researchers that participants may often feel intimidated or anxious when interacting with the researcher, and this occasion being our first interaction may have increased the likelihood of participants experiencing these emotions. To minimise this effect, it is advised that researchers build trust between themselves and the participants before a study commences (Wood et al., 2012). Therefore, initially I welcomed and introduced myself to the caregivers in Afrikaans or English – depending on the language of choice for each participant. I told them that I was a student from Stellenbosch University and that this was my first research project with caregivers of people with schizophrenia. Additionally, I shared that I was delighted to meet them, and that I was certain that I would

learn a great deal from them during our time together. I hoped that this would establish a degree of trust between me and the caregiver and patient.

I initiated the formal procedures of the study by explaining, to the caregivers and patients, the nature of the research and why they were chosen as participants. Thereafter, I provided each party with a demographic questionnaire (Appendix B), and the required informed consent documentation (please see Appendix C for the patient's consent form; for the caregiver's first consent form; and caregiver consent form 2). All parties could choose between Afrikaans and English forms. After this, I explained each section of the respective consent forms to both parties. Furthermore, I encouraged both parties to ask questions if certain aspects of the consent forms were unclear to them. When questions were raised, I addressed these immediately to clear any uncertainties that existed before we continued. After the informed consent documentation was explained, I asked the patient if he/she agreed that their caregiver may participate in my study. Only after the patient granted permission for their caregiver to participate did I turn to participants and ask them for the last time if they still wanted to participate in my study. Caregivers who agreed to take part were asked to sign the consent form. Thereafter, caregivers were asked to accompany me to the allocated room at the SRU where the interviews were to be conducted; in this time the patient remained in the welcoming room, while I conducted the interview with the caregiver.

The first appointment: the semi-structured interview. I asked participants open-ended questions on the caregiver burden, and the coping strategies that caregivers utilise when caring for a deinstitutionalised individual with schizophrenia, and from this followed participant cues, making sure to cover all aspects in the interview schedule. In my study, thirteen semi-structured interviews were conducted; one with each participant. The interviews were between 19 min and 122 min in duration. All interviews were audio recorded.

During the interviews, I encouraged the caregivers to openly and spontaneously answer the questions or responses that I posed to them. Furthermore, I assured the participants that there were no right or wrong answers to the questions, and that any information that they shared was important for my study. Lastly, I communicated to the caregivers that their stories were unique and that no one, but themselves, can be a better witness of the caregiver burden and coping phenomenon.

The first appointment: after the interview and debriefing of participants. After the interview session had ended, I thanked participants for their time and for sharing their experiences with me. By keeping in mind that the interviews were personal in nature, I

further informed participants that if they were feeling unsettled at this stage, or if they were to become unsettled in the future; to contact the registered mental healthcare clinician indicated on the informed consent forms. Subsequent to this, I introduced to participants a second stage to the study, which will be reported on elsewhere.

Techniques Used to Facilitate the Interviewing Process

During the interviews I primarily made use of the following techniques to facilitate discussion between the caregiver and myself.

Reflection. Reflection can be defined as a statement that is made by the listener when he/she wishes to emphasise the feelings or attitudes implicitly expressed in the story teller's communication. This technique is usually used by psychotherapists or counsellors when they hope to draw clients out so that the client's communication can be clarified (VandenBos & APA, 2015).

During interviews I frequently utilised this strategy at stages where I wanted to communicate to the caregiver that not only did I hear the story they were telling, but that I was also emotionally related to it. After reflecting on a narrative, it seemed as if participants felt that I could identify with their situation. As a result, caregivers further elaborated on the story being told at the moment, thus creating more and in-depth narrative that could be used for analysis.

Paraphrases. In addition to reflections, I made use of paraphrases to enhance narratives during interviews. Paraphrasing is closely related to reflection, but where reflections are made to emphasise the story teller's feelings or attitudes, paraphrases are used to show that the listener grasps the story being told. Thus, paraphrasing can be defined as the process where the listener aims to communicate back the meaning of a text or utterance made by the speaker in different words (VandenBos & APA, 2015). Similar to reflections, paraphrases serve to clarify the speaker's story, but are also used for the sake of brevity.

Rolling with the resistance. This technique is one of the cornerstones of Motivational Interviewing (MI), an approach to counselling that was developed to facilitate behaviour change (Miller & Rollnick, 2013). Resistance can be defined as reactions or defences created by the client that move the person away from change or gaining insights to reasons for change. In the case of my study with caregivers, I chose to use the term "rolling with the resistance" to refer to the moments when participants did not directly answer the questions posed to them. According to Miller and Rollnick (2013), people usually develop

resistance when they are not ready to change, or in the case of my interviews, when caregivers were not ready to address a question that possibly may have been difficult or sensitive for them.

In responding to this phenomenon, I allowed caregivers to react with resistance and to finish the line of narrative that they chose. However, thereafter I followed a guideline set by Miller and Rollnick (2013) where it is advised, for the moment, to shift the story teller's attention to a different topic. This allowed the caregiver to forget about the difficult topic that was being discussed. As a result, some participants lowered their defences – and at a later stage when I posed the same question to them, they offered a more question-related response.

Other aspects of verbal communication. I considered and monitored my verbal interactions during the interviews as well. This required active listening; I needed to be physically, cognitively and emotionally committed during the interviews. I had to focus on the narratives communicated during the interviews and to convey my presence to the participants. To facilitate this, the techniques of paraphrasing, as introduced above, was vital. In using my own words to feedback the essence of the caregivers' stories at times – both accurate and incorrect paraphrases elicited responses from the caregivers. Participants reacted upon these responses by further exploring the topics that were discussed at that particular stage. Furthermore, I summarised their verbal content before shifting to the next topic of discussion. As with paraphrasing, this allowed participants to validate my understanding of their stories. At times, when my summaries were inaccurate, caregivers corrected me – consequently producing accurate versions of their narratives for later analysis. Lastly, I also made use of probes when the caregivers gave an unclear or incomplete answer to a question or communication. A probe can be defined as a question or comment that stimulates further communication around the same topic and in this way providing clarification to the researcher (Sommer & Sommer, 1980). In this manner, I obtained clarification about topics when I felt that the caregiver's responses were incomplete or incomprehensible.

Aspects of non-verbal communication. The first technique with regards to non-verbal communication that I focused on throughout the interviews was to interact with an accepting, open, and warm body language. Being aware of my non-verbal communications was useful during the interviews, as the non-verbal interactions communicated my experiences and perceptions of the participants to them (Sommer & Sommer, 1980). In support of this, Sommer and Sommer (1980) point out the importance of appropriate eye

contact and suitable bodily positioning during interviews. On the one hand, it was important that I did not stare or gaze at the participants, as this might have led to the participant feeling uncomfortable (Sommer & Sommer, 1980). On the other hand, having no eye contact at all with the participants could have introduced its own challenges during interviews. For example, interviewees might have found it difficult to trust me in such a scenario (Sommer & Sommer, 1980). Therefore, I tried to judge the amount of eye contact with the caregivers that would make us both feel comfortable in the research environment. Furthermore, with regards to maintaining an interview friendly bodily posture, I positioned my chair with a slight angle towards the interviewee. I did this as I wanted to respect participants' personal space during the interviews. Throughout the interviews, and as prescribed by Sommer and Sommer (1980), I leaned slightly towards the participants when they were speaking, and sat up straight while posing questions or communicating with the caregivers. This conveyed my interest in the participants' stories, and my openness to receive the information from the caregivers during the interviews (Sommer & Sommer, 1980).

Increasing the Trustworthiness of the Study

As Shenton (2004) states, "the trustworthiness of qualitative research is often questioned" (p. 63). This is because some researchers question the credibility and validity of qualitative research findings (Shenton, 2004). In the past, and more recently, several writers on research methods, such as Lincoln and Guba (1985), Pope and Mays (1995), and Morrow (2005) have educated qualitative researchers on how to increase the trustworthiness of their studies. Therefore, being guided by Lincoln and Guba (1985), Pope and Mays (1995), and Morrow (2005), I have taken several measures to increase the trustworthiness of my study.

According to Lincoln and Guba (1985), four criteria should be considered in order to increase the trustworthiness or validity of qualitative work. These criteria are: credibility, confirmability, dependability, and transferability. I mainly draw on the literature of Shenton (2004) to address these four criteria as outlined by Lincoln and Guba (1985). Lastly, Morrow (2005) adds a fifth criterion by stating that it is fundamental for the researcher to acknowledge the ways that he/she may have influenced the research process and findings. Therefore, it is advised that the researcher reflect on the study and its processes, and make this information known to others to consider when they may want to replicate the reported study in the future. Next, the text defines these five factors, and continues by explaining how I have addressed them in my study.

Credibility. According to Shenton (2004), the factor of credibility is one of the most fundamental properties to address in qualitative work. This is because this concept deals with the question: "how congruent are the findings with reality" (Merriam as cited in Shenton, 2004, p. 64). Simply put, does the study measure(s) or test(s) what is actually intended to be measured (Shenton, 2004). Shenton's (2004) article introduces 13 ways that researchers can intervene to increase their chances of producing credible work. However, I have mainly addressed six of these strategies in my study.

First, Shenton (2004) suggests that the researcher discloses "any personal and professional information relevant to the phenomenon under study" (p. 68). In response to this recommendation I include details concerning my background, qualifications, and experience with schizophrenia and schizophrenia caregiving. I have introduced this text later in this chapter in the *Researcher-reflexivity* section.

Second, Shenton (2004) proposes that researchers should examine previous research in the field of the phenomenon under investigation to increase the credibility of their work; as researcher, I have also acted in accordance with this suggestion. As stated earlier in this thesis, and as introduced in the literature review in Chapter Three, I have examined previous research findings in the field of schizophrenia and schizophrenia caregiving and coping.

Third, Shenton (2004) states that it is advised that the researchers familiarise themselves with the culture of participating individuals or the organisations before data collection is initiated to increase the credibility of the findings. I have addressed this guideline by attending scheduled meetings at the SRU where my study was conducted. In this way, I familiarised myself not only with the physical research environment, but also with the staff and the way the facility operates. Furthermore, as will become clear later in this section, I have also aimed at familiarising myself with the context of the schizophrenia-caregiver by having frequent telephonic conversations with my aunt who has been caring for my cousin who has schizophrenia. In these conversations, I noted the stories that my aunt told me and in essence these calls were fundamental in increasing my understanding of the phenomenon, and population being studied.

Fourth, Shenton (2004) recommends frequent debriefing sessions with research supervisor(s). In addressing this I have, from the start of conducting and writing-up of my research, been in supervision sessions with my study supervisors. These supervision sessions assisted me academically – by broadening my outlook on the project and my experience related to it. The meetings further provided a space where I could develop my ideas and

interpretations of, specifically, the research findings. Additionally, these supervision sessions assisted me emotionally throughout the course of the project.

Fifth, Shenton (2004) encourages researchers to discuss the research project with their colleagues, peers, and other academics and to note insights gained from these encounters. These "peer scrutiny" (Shenton, 2004, p. 67) opportunities can open the researcher to a different way of making sense of the study and its findings. Furthermore, it may serve to challenge the assumptions made by the researcher, whose closeness to the project frequently inhibits his/her ability to view it with real detachment (Shenton, 2004). I have abided by this guideline by discussing my work and ideas with fellow Masters Degree Psychology students who were completing their studies with me. By listening to fellow students' critical opinions, my understanding and interpretations of the research were challenged, broadened, or confirmed at times. Ultimately, my realisations became incorporated into my work as I aimed at producing a more credible report of caregivers' experiences.

Sixth, both Shenton (2004), and Pope and Mays (1995), argue that another way to increase the credibility of one's work is to introduce member checks, or respondent validation opportunities to the study procedures. In short, member checks can be defined as obtaining the participant's input on the research findings and the investigator's interpretations (Shenton, 2004). Interestingly, Guba and Lincoln (as cited in Shenton, 2004) consider respondent validation to be "the single most important provision that can be made to bolster a study's credibility" (p. 68).[2]

According to Shenton (2004), there are a number of ways to execute the member check process. One way, for example, is by allowing participants to read the transcriptions of their narratives and confirm that their stories were accurately transcribed. Another way to obtain respondent validation, and the strategy which I utilised in my study, is for the investigator to communicate the results that emerged, and his/her interpretations made from the results, to the participants. In response to this, participants should be offered the opportunity to verify or challenge the conclusions made by the researcher. Finally, the resulting outcomes from this interaction(s) should be incorporated into the researcher's write-up of the work.

[2] For practical reasons, it was not possible to conduct member checks with caregivers before the hand-in and publication of this thesis. It should however be noted that member checks, as described above, will be conducted through a focus group session before any information produced in this thesis is disseminated through the form of journal articles.

Respondent validation occurred during a focus group meeting. Before the focus group session was conducted I initiated the proceedings with a presentation of my research findings. I further informed caregivers about my interpretations of their collective narratives – in other words the content found in Chapter Six of this thesis. Thereafter, participants were encouraged to comment on the content presented. Participants' feedback was noted and incorporated into the write-up of my thesis.

Confirmability. According to Shenton (2004), the term confirmability refers to the notion that research findings are objective, rather than an expression of the researcher's ideas and characteristics. Objectivity can be defined in two ways. First, it implies that judgements and conclusions made by the researcher are based on the data collected, rather than subjective factors such as the investigator's personal emotions, views, and experiences (VandenBos & APA, 2015). Second, objective research entails that its measurements, research techniques, and observations are as free from researcher bias as possible (VandenBos & APA, 2015). Patton, as cited in Shenton (2004), however, argues that it is difficult to guarantee "real objectivity" (Shenton, 2004, p. 72) in qualitative research. This is because in qualitative research approaches, the data collection instrument(s) are often designed by the researcher, and the researcher is actively involved in the execution or administration of the data collecting instrument(s). As a result, the intrusion of the investigator's biases is inescapable (Shenton, 2004). As intervention, "steps must be taken to help ensure as far as possible that the work's findings are the result of the experiences and ideas of the informants" (Shenton, 2004, p. 72).

One way of increasing confirmability is to include triangulation during data collection or analysis. Triangulation involves the process of confirming a research question by collecting data from multiple sources (VandenBos & APA, 2015). One way to do this is by methodological triangulation. To introduce methodological triangulation, the researcher may choose to utilise more than one data collection technique to confirm the study findings (VandenBos & APA, 2015). In essence, I incorporated methodological triangulation in my work by introducing the photovoice collecting technique – however, as stated earlier, the findings from this additional data collection strategy are reported elsewhere and not discussed in this thesis. Alternatively, more than one researcher can analyse the data for triangulation. This procedure is known as investigator triangulation; but I did not introduce this aspect in my study (VandenBos & APA, 2015).

Another way of increasing confirmability is for the researcher to admit his/her own predispositions towards the phenomenon being investigated, as it would ultimately influence

the manner in which the data is approached and analysed (Shenton, 2004). In doing this I inform the reader, and others who may want to replicate this particular project in the future, about my predispositions towards the caregiver experience and how it may have influenced the formulation of my research. My predispositions towards the caregiver experience are discussed later in this chapter in the Researcher-reflexivity section.

Dependability. Dependability as a concept refers to whether the study findings would be the same if the research was to be replicated by another researcher (Lincoln & Guba, 1985; Shenton, 2004). In order to increase the dependability of a study, making it more trustworthy, the researcher should describe "the processes within the study… in detail" (Shenton, 2004, p. 71). Furthermore, describing the study procedures in detail will allow others to assess the degree to which proper research methods have been followed. According to Shenton (2004), this can be achieved in three ways: describing the research design and its implementation; describing in detail what the researcher did in the field; and evaluating the effectiveness of the research processes.

In response to Shenton's (2004) three recommendations, I have, first, comprehensively discussed the research design and approach, the research setting, sampling strategies, and data collection methods earlier in this chapter. Second, I have also, earlier in this chapter, included a section to describe in detail the procedures that took place "on the day the day of the interviews" to inform the reader of the research approach that was followed in my work. Lastly, the thesis will at a later stage evaluate the effectiveness of the research processes. In order to do so, the text will introduce strengths and limitations of my work and also provide recommendations for other researchers who may want to replicate my study in the future.

Transferability. Transferability as a concept "is concerned with the extent to which the findings of one study can be applied to other situations" or other populations apart from the study sample (Merriman as cited in Shenton, 2004, p. 69). Simply put, transferability addresses the question: *Will other schizophrenia caregivers in, for example another country, report similar experiences to the caregivers in my study?* It cannot be ignored that in qualitative research, the relatively small participant sample and specific contextual factors of the participants and the study environment may make it "impossible" to show if the study findings and conclusions are applicable in other populations or scenarios (Shenton, 2004, p. 69). However, according to Shenton (2004), the primary way to enhance transferability in qualitative work is to provide a detailed description of the context in which the study took place. Furthermore, readers should receive an in-depth illustration of the phenomenon that

was investigated. These two factors are fundamental contributors in enhancing transferability, as this information can enable the reader, other professionals, and future researchers to compare different populations with each other and the relevance of specific research findings to the different contexts. Nevertheless, Shenton's (2004) paper informs us that, ultimately, after perusing the written study report, "readers must determine how far they can be confident in transferring to other situations the results and conclusions presented" (Shenton, 2004, p. 70). The text next motivates how transferability was increased in my work.

First, as stated, it is required that the researcher provide the reader with contextual information related to the study. In fulfilment of this requirement, the text presented in this thesis serves to contextualise the different aspects of this research. For example, by including a theoretical framework, I have informed the reader about the way that "I made sense of the phenomena under investigation". An alternative example may be found earlier in this chapter where I positioned the reader with regards to the research setting(s), and the participant inclusion criteria. Additionally, when reporting the results, the thesis introduces a detailed description of the sample of caregivers who participated in my study.

Second, Shenton (2004) advises researchers to produce a thick description of the phenomenon being studied. In order to do this, I have presented a literature review that aims at providing a context for the schizophrenia-caregiver relationship as an area of study. Moreover, later in the thesis, a context for caregiver experiences is provided by the specific reports given by the caregivers in my study. However, I go further than merely reporting the study findings. By making use of theory, I interpret the caregiver-experience as it unfolded in my work.

Researcher-reflexivity. In this section I reflect on two factors that may have influenced the way that my study was conducted. These factors are:

1. My background, qualifications, and experience with schizophrenia and schizophrenia caregiving.
2. My predispositions towards the phenomenon being investigated.

My background, qualifications, and experience with schizophrenia and schizophrenia caregiving. I wish to disclose some background information that may have influenced the way in which I approached my study. I am a White male, 26 years of age, and grew up in a middle-economic bracket household. Against this, most of the participants in my study were Coloured females who were between 10 and 46 years older than me and they

indicated that their economic income falls in the low-income bracket. This factor may have influenced me consciously or unconsciously in the way that I approached the interviews. One example might be when I doubted my ability to relate to individuals who differ from me in multiple life-domains. It may also be the case that caregivers decided to withdraw from sharing sensitive information with me because I was far younger than them.

Furthermore, I have completed secondary level education and, at the time of my study, was holding two degrees at a tertiary level – with the highest qualification obtained being an Honours Degree in Psychology. I also informed participants during the informed consent procedures that I was completing my Masters Degree in Psychology at Stellenbosch University. I suspect that, at times, some participants may have felt intimidated by this. In support of this I specifically refer to the instances when participants addressed me as "doctor", instead of calling me "Mister" or "Divan". This may have influenced the way in which participants shared their narratives with me. Occassionaly, it felt as if caregivers viewed me as a figure of authority. Also, participants frequently asked my advice for solving difficulties that they had experienced.

Prior to my study, I had limited experiences of schizophrenia caregiving. Two life experiences shaped my understanding and expectations of schizophrenia caregiving. First, I have a cousin who was diagnosed with schizophrenia (approximately six years ago). I have had periodic interactions with him and his caregivers – his mother, father, and brother – over the past decade. These meetings provided me with glimpses of the caregiver experiences. In addition to this, I have been in telephonic contact with my aunt over the past years. During these calls, I commonly asked about her experiences, or she initiated conversations about the difficulties she was experiencing. Thus, before conducting my study, I knew about my cousin's substance abuse; denial about being ill; refusal to initiate antipsychotic treatment; and poor adherence to treatment. I also knew about my aunt's experiences of uncertainty, worry, guilt, and helplessness that accompanied the schizophrenia caregiver role. Second, I have been a volunteer worker at SPH for the past four years. Here, I have encountered patients with schizophrenia and witnessed the affects of the disorder in multiple life domains – physiological, psychological, and social – of the person with it. This experience at SPH, together with that of having a cousin with schizophrenia, familiarised me, to some extent, with what to expect during my interviews. At this stage, I regard it appropriate to mention that during my study I have experienced a range of emotions that I had not experienced before.

For example, I was deeply moved by and empathised with the intensity of some caregivers' emotional experiences, and at times I became aware of my vulnerabilities related to schizophrenia. Caregivers like Skollie reported that their relative with schizophrenia was one of a twin. Coincidently, I am also one of a twin. I was prompted to think about the concepts of equifinality, that different starts may result in similar endings, and multifinality, that similar starts can lead to dissimilar ends; I thought: *My brother and I could have been the person(s) with schizophrenia.* Yet, I do believe that my vulnerabilities in this regard did not negatively influence the manner in which I approached the interviews or reported the results.

My predispositions towards the phenomenon being investigated. As indicated above, my predispositions were mainly influenced by my experiences with my family members that experience the caregiving of a person with schizophrenia, and my volunteer work at SPH. I wish to disclose that at SPH I primarily encountered patients who display poor bio-psycho-social functioning. My continual exposure to patients who show signs of antipsychotic medication side effects, being schizophrenia symptomatic, and patients having limited social interaction, had influenced my understanding and expectations of other deinstitutionalised individuals who also have schizophrenia. I did not expect that a considerable number of patients, who were being cared for by caregivers in my study, would not present with behaviours that I had encountered at SPH.

However, I am confident in saying that my outlook on the person with schizophrenia was forever changed very early in my study. Also, I do believe that my preconceptions did not have a negative impact on how I approached my study.

Data Analysis

All of the interviews were audio-recorded on a voice recorder. The audio-recordings were downloaded onto my computer after each interview session. Thereafter, professional transcription services were employed to transcribe verbatim copies of the narratives (please see Appendix D for contracts of confidentiality that was signed by service providers).

It is, furthermore, important to note that I immersed myself with the narratives directly after the audio-recordings were downloaded onto my computer. I did this by listening to the interviews over headphones. I did this for two reasons. The first reason was that I wanted to familiarise myself with the data from an early stage – this process is fundamental when using Thematic Analysis (TA) to generate research findings (it will become clear later in this chapter that I utilised TA in this project) (Braun & Clarke, 2006).

Being familiar with caregivers' experiences and stories enhanced my understanding about the respective phenomena that were investigated. My enhanced understanding provided the opportunity for me to probe more specific topics during the interviews that followed. The second reason for immediate immersion was that I followed the guidelines set by Baker and Edwards (2012). According to Baker and Edwards (2012), in qualitative research, the sampling, data collection, and data analysis phases of a particular study are integrated, rather than separate events.

After I received the transcriptions, the text was entered into Atlas.ti version 7. Atlas.ti is computer based qualitative data management software. Thereafter, the semi-structured interviews were analysed using TA, as described by Braun and Clarke (2006). The text will now conclude this section by describing the process of TA and how I utilised it in my study.

Using Thematic Analysis to Analyse the Data

According to Braun and Clarke (2006) TA helps to identify, analyse and report patterns found in the data. Furthermore, TA organises and describes data in particular detail and also interprets different aspects of the research topic. This procedure can be divided into a number of steps.

1. The first step is to familiarise oneself with the data (Braun & Clarke, 2006). During this stage, Braun and Clarke (2006) advise that the researcher personally transcribe the interviews. This is followed by immersing oneself with the narratives by reading them a few times and jotting down initial thoughts around the data collected. As mentioned earlier, I made use of transcription services to transcribe the audio-recordings of the interviews. Thus, I could not immerse myself with the data in this manner. However, to become familiar with the narratives, I replayed each interview over earphones at home; while jotting down my ideas related to the story. At a later stage, after I had received the transcriptions, I read and reread each transcript. I did this to further immerse myself in the data set and to become more aware of the stories that were being told by the caregivers. This was accompanied by a further jotting down of interesting patterns, which I became aware of at each particular stage.
2. The second step is to generate initial codes from the data set (Braun & Clarke, 2006). Codes represent a feature of the data – may it be latent or semantic, as long as it appears interesting to the researcher. Furthermore, a code serves as the most fundamental element of the raw data; which can be interpreted and related to the

phenomenon being studied in a meaningful way (Braun & Clarke, 2006). In this phase, the researcher codes for interesting features of the data in a systematic manner across the complete data set, additionally collating data pertinent to each code (Braun & Clarke, 2006). I followed this guideline as well. The use of Atlas.ti facilitated this process, as I could mark and link various interesting quotes from participants. As a result, I also found it easier to view patterns that occurred throughout the complete data set together.

3. After this, the third step is to search for themes from the data set (Braun & Clarke, 2006). This phase marks the gathering of respective codes together and arranging all the relevant codes in potential themes. Where generating codes were closely related to the raw data – in creating themes, the researcher now views the data more broadly. Here, it is required that the researcher starts to analyse the collated codes, while trying to group them in an overarching group or theme(s). Additionally, themes can also consist of sub-themes that build that particular theme. In my study, this stage was already addressed earlier, at *step 2*, as Atlas.ti made it easier for me to group all the codes together (as described in the above paragraph). Consequently, I grouped various codes into respective themes and sub-themes at this stage.
4. The fourth step is to refine the potential themes that were created at *step 3* (Braun & Clarke, 2006). Fundamental to this stage is the process of checking if the potential themes fit in relation to the coded phrases and the complete data set. First, it may become apparent during this stage that some candidate themes are not actually themes – for example, there are not enough data to substantiate it for a theme (Braun & Clarke, 2006). Consequently, in this phase some themes may form sub-themes, or merge with one another, or even be separated in two or more different themes. Additionally, I also grouped the themes which emerged into theme families (theme families are explained in Chapter Five). Once the potential themes form a coherent pattern the researcher considers the validity of the themes against the complete data set. In other words, the researcher has to decide if the themes represent the data set as a whole. In this step the data set, together with the theoretical framework(s) that structure the findings are considered. If the researcher is satisfied that the themes represent the complete data set and can be viewed from the theoretical approach(es) of the study, this phase is completed (Braun & Clarke, 2006).
5. The fifth step is to term and define each theme (Braun & Clarke, 2006). It is important to assign relevant names to each theme and sub-theme, and to ensure that

the names reflect the findings reported. Furthermore, each theme needs to be defined and described; what does the theme convey in relation to the phenomenon being studied? (Braun & Clarke, 2006). I abided by this guideline in terming themes with schizophrenia relevant terminology, as it appears in Chapter Five.

6. After the researcher has successfully completed steps one to five, and as a result, has a set of fully worked-out themes, the sixth step is to report the themes in a document (Braun & Clarke, 2006). It is essential for the researcher to covey the "complicated story of your data in a way which convinces the reader of the merit and validity of your analysis" (Braun & Clarke, 2006, p. 93). In the write-up of the findings, quotes from participants are used to demonstrate the prevalence of the themes and sub-themes, as it is found in the raw data. These are then interpreted and reported in such a manner that it forms the basis of the argument in relation to your research question(s) (Braun & Clarke, 2006). Ultimately, this step was executed in the write-up of the results and discussion chapters of this thesis.

Ethical Considerations

To ensure that my study was ethically sound; and to prevent any possible harm to participants and myself, my research complied with certain research characteristics. These characteristics include obtaining ethical approval to conduct my work, gaining informed consent from participants, participant anonymity and confidentiality, and providing remuneration to participants. The text discusses the ethical considerations below.

Ethical Approval

I applied for ethical approval from the Research Ethics Committee of the Faculty of Health Sciences at Stellenbosch University. Furthermore, my project was conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, the South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

Ethical approval for my study was received on 31 August 2016 (reference number: S16/07/130). Ethical approval documentation can be viewed in Appendix E. The recruitment of participants and data collection was initiated after this date.

Informed Consent

By introducing the informed consent process in research, the researcher ensures that participants are fully informed about the study procedures and that they give permission to be part of the project before data collection commences (Willig, 2013). Willig (2013) further point out that it is important to obtain informed consent from participants for four reasons. First, this procedure involves informing participants about the overall purpose of the research and the core aspects of the design. Second, it also explains to the participants any foreseen risks, and third, the potential benefits from participating in the study. Fourth, informed consent includes obtaining the voluntary participation of the individuals involved and communicates to participants their right to withdraw from the research at any time if they so wish.

Informing participants of my study. Informed consent was received from both the caregivers who participated in my study and the patients that were being cared for, before data collection procedures started. This explains why, as introduced earlier, both the caregiver and patient were invited to the first data collection appointment. In this process the research procedures and the relevance of the study were explained to the participant and patient; any uncertainties or questions on the part of the caregivers or patients were answered. Informed consent from both parties included permission for caregivers to take part in the semi-structured interview session, the photo discussion, and the focus group appointment.

Informed consent in general further also stipulated that the caregiver's story may be audio-record and that transcription of their narratives may be used for data analysis and academic purposes. Thereafter, interviews started.

Additionally, it is important to point out that informed consent forms were available to participants in Afrikaans and English. The English version of the consent form was professionally translated into Afrikaans before the study started. Moreover, each participant was provided with an extra copy of their consent form(s) to take home with them. The extra copy was made available to the patients and caregivers in case that they wanted to utilise or contact resources outlined on it in the future.

Anticipated risks. The only foreseen risk for participants in joining this study might have resulted from the personal nature of the qualitative interviews; due to this, participants might have become vulnerable to experiences of discomfort and stress. If this were to be the case, participants were referred to a HPCSA registered clinical psychologist. Dr Avril Cowlin, a psychologist in private practice, was approached to provide her services to

participants if needed. For this, the project had sufficient funds allocated to pay for six sessions of mental healthcare at the private practitioner for each person so referred. Thereafter, if it was needed, Dr Cowlin assisted her client in locating an appropriate mental healthcare clinician in the state healthcare system. I need to mention that at the end of my data collection procedures, and up to the date of writing this thesis, no participant was referred or has requested to be referred to Dr Cowlin for psychotherapy.

Potential benefits. Participants were informed that there would be no direct personal benefit from participating, however the consent forms stipulated that participants who decided to participate may help many healthcare providers and policy makers in gaining a better understanding of the experiences and needs of caregivers and how to provide adequate support.

Voluntary participation and participant withdrawal. Participants were informed that their participation in the study was completely voluntary. Furthermore, Willig (2013) states that the researcher should communicate to participants their right to withdraw from participating in the study, without any penalisation. Thus, I informed caregivers about their right to withdraw from the study at any stage, with no negative effect from this during the informed consent process.

Anonymity and Confidentiality

The terms anonymity and confidentiality can be seen as closely related to each another, but distinct differences exist when looking at the definitions. It is therefore needed to cover both aspects of these ethical requirements in research.

To start, the concept of anonymity is two-fold. First, participant anonymity may be guaranteed when the research does not obtain any form of identifying data from the participants (e.g., name, contact details, etc.). Alternatively, when participants can be linked to the data, the researcher should intervene, as far as possible, so that participants cannot be identified from the data (VandenBos & APA, 2015). Additionally, the notion of confidentiality involves the researcher's promise not to disclose information about participants to others who are not involved with the project. As a result, data collected from a participant should only be identifiable to the researcher and others who are involved with the specific study (VandenBos & APA, 2015).

My study and procedures related to it did however collect information that could identify participants; therefore the study design had to be developed to respect confidentiality and participant anonymity. I did this in the following ways:

To respect confidentiality, any details of participants were only known to me, Prof. Swartz, Dr. Kilian, the principal investigator of the schizophrenia section of the SRP, the nurse that was present at the SRU on the days of the interviews, and the transcription service providers. It is necessary to mention that the two transcribers who worked on my study both signed confidentiality contracts before receiving the audio-recordings. Additionally, digital information (the audio recordings and photographs) was stored on my password protected computer, and the hard copies of the biographical information of participants were secured in a lock protected cabinet in my room.

To guarantee participant anonymity, pseudonyms were assigned to each participant and index patients to replace their real identity before any information collected from my study reached anyone who has not been mentioned above. In this manner, my study ensured that participants' identity remained anonymous to the outside world and that no information could be linked to specific participants.

Remuneration for Participation

Participants were not paid for their participation in my study. Instead, participants did receive R150.00 for each interview session to cover their travel expenses to SPH, and as compensation for the time that they donated to the study. Participants were also told that there were no additional expenses linked to joining my study. Additionally, refreshments were made available to participants before and after the interviews.

To summarise, this chapter explored the methodology that guided research procedures. The next chapter reports the results that emerged after data analysis.

CHAPTER FIVE

RESULTS

This chapter reports on the findings that emerged from analysing the transcripts of the interviews that were conducted in my study. However, before the results are presented, a description of the study participants (13 caregivers) is provided. A detailed description of each of the participants can further be found in Appendix F. As explained earlier, participants' and index patients' names were replaced with pseudonyms to respect rights to anonymity (please see Table 1 for caregivers' self-chosen pseudonyms). All male and female patients' names are substituted with pseudonym as well. Also, as most interviews were conducted in Afrikaans, I offer English translations of narratives – it should be noted that caregivers' voices will be reported first; thereafter the translation of the content follows.

Describing the Caregivers

The participant sample was marked by diversity in various domains (please see Table 1 below for a summary of the demographic information of caregivers). These diversities included differences in ethnicity and age; furthermore, the caregiver's relationship to the patient, caregiver's annual financial income, and the period of being a caregiver for the person with schizophrenia. The text illustrates these diversities in more detail below:

Ten of the participants identified themselves as Coloured individuals, one participant as Black, and one as White[3]. One participant did not disclose her ethnicity to me.

Most caregivers were aged 53 years or older, but there was a wide age range, with the oldest being 73 and the youngest 32. The median being 58 years of age.

All, except one, were family members (first degree relatives) of the person who was living with schizophrenia. There were nine mothers, two fathers, and one sister. Jack was the only caregiver who was not a family member of the patient; at the time of the interviews Jack was the boyfriend of a patient, a woman with schizophrenia. All participants were living in the same house as the person with schizophrenia, or on the same premises (for example, the patients lived in an apartment in the backyard of the caregiver). Caregivers had

[3]These categories are contested and have a problematic history in light of apartheid and earlier discriminatory systems. I do not regard race as anything other than a social construct; these categories still have meaning in contemporary South Africa as they broadly reflect patterns of discrimination and they are still used in many contexts – for example, in the implementation of employment equity legislation.

been caring for the person with schizophrenia for between 3 and 30 years, with a mean of 10.6 years and a median of 8 years.

The difference in caregivers' annual financial income was significant. While two caregivers did not disclose their annual income; caregivers' income varied from R 16 800 to R 180 000 annually. The mean annual financial income was calculated as R 83 363 per caregiver per annum, and the median income was R72 000 – most participants were living in poverty.

Lastly, on the one hand; nine caregivers provided care to male patients. On the other hand, four caregivers were providing care for female patients. It should be noted that the patient in this scenario refers to the person with schizophrenia being cared for by the caregiver who consented to participation in my study – as some caregivers provided care for more than one person with a mental illness or schizophrenia.

Table 1

Demographic Information of Caregivers

Pseudonym	**Ethnic group**	**Age**	**Gender**	**Relationship to patient**	**Annual income and employment status**	**Duration being a caregiver**	**Patient being cared for**
Cassey^	Coloured	69	F	Mother	R 72 000 (Retired)	15 years	Chris
Maryna^	Coloured	72	F	Mother	R 16 800 (Unemployed)	30 years	Martin
Skollie^	Coloured	73	M	Father	R 144 000 (Retired)	16 years	Shirley*
Sheila^	Coloured	67	F	Mother	Did not indicate annual income (Unemployed)	15 years	Shirley*
Doris^	Coloured	67	F	Mother	R 180 000 (Unemployed)	9 years	Dawn
Betty	Coloured	58	F	Mother	Did not indicate annual income (Employed)	6 years	Brett**
Charlie	White	60	M	Father	R 120 000 (Retired)	8 years	Conrad
Zuby	Did not indicate ethnic classification	58	F	Mother	R 84 000 (Employed)	10 years	Peter
Natalie	Coloured	36	F	Sister	R 20 000 (Employed)	5 years	Brett**
Jack	Black	32	M	Boyfriend	R 30 000 (Employed)	3 years	Jessica
Zelda	Coloured	53	F	Mother	R 180 000 (Employed)	7 years	Mark
Olivia	Coloured	54	F	Mother	R 34 200	6 years	Alfred

					(Unemployed)		
Suzette	Coloured	56	F	Mother	R 36 000 (Employed)	8 years	Fred

Note. ^ Caregivers were caring for more than one relative with schizophrenia.

* Shirley is the daughter of Skollie and Sheila and therefore was the index patient for both caregivers.

** Brett is the relative of both Betty and Natalie – therefore the index patient for both caregivers.

Results

By exploring caregivers' subjective experiences of caring for deinstitutionalised individuals with schizophrenia, my study mainly aimed at generating knowledge of the phenomena of caregiver burden, and caregiver coping. However, during analysis it also became apparent that intertwined with the narratives on caregiver burden and coping, caregivers' stories encapsulated a description of how they perceived the patient(s) who they cared for at home. While it is beyond the scope of my study's aims, I considered it important to provide the reader with caregivers' description of the patient, as this familiarises the reader with the patient(s) who were being cared for.

Despite the differences in individuals' ethnicity and age, their relationship to the patient, caregivers' annual financial income, and the period of being a caregiver for the person with schizophrenia, several themes appeared to be common across the experiences of participants. Participants' experiences of each research aim are reported in this section. The reporting of my study's findings begins with caregivers' description of the patient. This is followed by the reporting of the results generated in the domains of caregiver burden, and caregiver coping.

Caregivers' Description of the Person Living with Schizophrenia

This section presents the caregiver's description of the patient. The respective themes and sub-themes derived during TA are summarised in Table 2. Thereafter the results are reported.

Table 2

Themes and Related Sub-themes Related to Caregivers' Perception of the Patient

The Caregiver's Perception of the Patient			
Theme 1	The person before the onset of schizophrenia		
Sub-themes (1.1-1.3)	Traumatic experience by patient before onset of schizophrenia	Patients' educational experiences	The biopsychosocial behaviour changes before the onset of schizophrenia
Theme 2	Onset of schizophrenia		
Theme 3	Patients' behaviour after becoming ill		
Sub-themes (3.1-3.4)	The easy patient	The difficult patient	Caregivers' reports of a high functioning patient
	Caregivers' reports of a low functioning patient		
Theme 4	Caregivers' observations of the effects of patient's medication use		
Sub-themes (4.1-4.2)	Side effects of antipsychotic medication	Unresponsive to antipsychotic medication	
Theme 5	Recovery enabling factors		
Theme 6	Recovery hindering factors		

Caregivers' perception of the person with schizophrenia can be categorised into six themes: 1) the person before the onset of schizophrenia, 2) onset of schizophrenia, 3) patients' behaviour after becoming ill, 4) caregivers' observations of the effects of patient's medication use, 5) recovery enabling factors, and 6) recovery hindering factors. As can be seen in Table 2, some of the themes are further divided into sub-themes. These themes and sub-themes are operationally defined and reported below:

Theme 1: The person before the onset of schizophrenia. This theme includes narratives that focused on a description of the patient, his/her behaviours, developmental phases, and life events that occurred, as perceived by the caregiver before the onset of

schizophrenia. Thus, the theme represents various happenings in the patient's life before the caregiver had any suspicion that the patient may be displaying symptoms of schizophrenia. The three sub-themes, which more accurately describe the patients who were being cared for by the caregivers in my study, are presented below:

Sub-theme 1.1: Traumatic experience by patient before onset of schizophrenia.

This sub-theme encompasses stories that caregivers voiced regarding patients' experiences of traumatic events prior to the onset of schizophrenia. Traumatic experiences can be defined as "any disturbing experience that results in significant fear, helplessness, dissociation, confusion, or other disruptive feelings intense enough to have a long-lasting negative effect on a person's attitudes, behaviour, and other aspects of functioning" (VandenBos & APA, 2015, p. 1104). Traumatic experiences may be inflicted on the person by another individual – such as acts of rape, assault, or war exposure. It can also be caused by nature – for example, natural disasters that often challenges the person's view of the world as fair, secure and predictable (VandenBos & APA, 2015). Therefore, VandenBos and APA (2015) include any serious injury that a person may experience, whether caused by another person or by nature, as a traumatic experience.

In my study five caregivers reported that the patient who was being cared for experienced or bore witness to events that fall into the above definition of traumatic experiences. First, Cassey explained how her son, who has been diagnosed with schizophrenia, reacted to the events during his father's suicide. Her son's reaction was predominantly marked by characteristics of shock and dissociation; thereafter a doctor admitted her son to Stikland Psychiatric Hospital:

> *Ja, toe- toe- toe hy nou- toe- na sy pa sê dood, ja, toe is sy pa nog gesterf, dingus het, toe was hy- toe lei hy so aan skok dat hy- dat hy net- hy kan- hy kon geregeer het of niks nie, hy kon net- hy het net so uitgestaar, en toe gaan hy af na- sit en- gaan sit in die park en toe sien ek iemand om- om te gaan kyk na hom, en so aan, en toe vat ek hom dokter toe, toe het die dokter vir hom 'n inspuiting gegee, maar die dokter het ook vir hom in-gebook by- by- by Stikland.*
>
> *Yes, when- when- when he now- after his father's death, yes, then his father was still passed away, something, he was- he suffered from shock so much that he- that he only- he could react or nothing, he could only, he only stared outwardly, and then he went down to- sit and- to sit in the park and then I saw someone to- to go and look at him, and then I took him to the doctor, then the doctor gave him an injection, but the*

doctor also booked him in at- at- at Stikland.

Second, Charlie also reported that his son experienced a traumatic event. This event occurred at the time when his son was attacked and held hostage during a burglary at home. Moreover, when I asked about Charlie's feelings about his son's diagnosis of schizophrenia, he commented that he was not surprised and attributed the onset of schizophrenia to this traumatic experience:

> Divan: *Ek wil nou weer so bietjie net die tyd, in tyd 'n bietjie beweeg, hoe't jy gevoel op die dag toe jy uitvind hy's siek? Hy't die diagnose van skisofrenie? Of* hulle dink *hy't skisofrenie?*
> Charlie: *Uhm, hoe sê ek, ek was [pouse] ek was nie baie verbaas nie…want ek het, ek het ook al geweet van die dae wat hy wat wat hulle hom amper doodgemaak het in die kas toegesluit het en daai ding, en sy [pouse] terugtrokkenheid op skool. Hy was 'n uitblinker op sport, sport was dit rugby, atletiek, 100%, hy was baie baie goed…en [pouse] dis hier op hoërskool wat wat dinge begin verander het.*
>
> Divan: *I want to again now just the time, move in time, how did you feel the day you found out that he's sick? That he has the diagnosis of schizophrenia? Or they thought he had schizophrenia?*
> Charlie: *Uhm, how do I say, I was [pause] I wasn't very surprised… because I had, I had also already known of the days that he that that they almost killed him locked him in the cupboard and that stuff, and his [pause] withdrawal at school. He was outstanding at sport, sport it was rugby, athletics, 100%, he was very very good… and [pause] it's here around high school that that things started to change.*

Lastly, Natalie also reported that her brother had experienced trauma. Here, Natalie reflected on the time when her brother was physically abused by his ex-wife one night when he was asleep:

> *Maar nou wil ek jou gou vertel van die vrou, en toe het hulle mos nou, daar was een nag wat ek wakker gelê het, en Brett skree in sy plek, like skree. Ek dink, nou gaan kyk ek, ek maak nie vir hulle bewus nie ek gaan, ek gaan nou vir hulle kyk en, hy't gelê en slaap, die vrou het letterlik sy penis so gevat en gedraai binne in sy slaap…*
>
> *But now I want to quickly tell you about the woman, and then they did, there was one night where I lay awake, and Brett was screaming in his place, like screaming. I was*

> *thinking, now I went to look, I didn't let them know that I was going, I was going to watch them now and, he was lying and sleeping, and the woman literally took his penis like this and was twisting it in his sleep…*

Sub-theme 1.2: Patients' educational experiences. This sub-theme consists of narratives that dealt with aspects of patients' educational background. Any experiences or reflections related to the patients' primary, secondary, or tertiary schooling, as perceived by caregivers are included in this sub-theme.

Six caregivers produced narratives about the patient's educational background. On the one end of the spectrum, caregivers reported that patients experienced academic difficulties; had to drop out of school before completion of their course; and patient problematic behaviour at school. On the other end, Skollie and Sheila reported that it was possible, eventually, for their daughter to further her education after being diagnosed with schizophrenia.

Charlie stated that his son experienced academic difficulties and further told that his son was always behind in his school work: *"hy't ook 'n leerprobleem gehad daai tyd… Hy was net vir my bietjie agter, hy't met agter, hy was altyd agter gewees met skoolwerk." ("he also had a learning problem at that time… He was for me just a bit behind, he was behind with, he was always behind with school work.")*. Similarly, Natalie explained how her brother's reading difficulties caused him to struggle academically and as a result he only managed to progress to Grade 11 of secondary school:

> *hy't mos skool gegaan né hy was baie lief vir skoolgaan. Maar omdat hy nie kon gelees het lekker op skool nie, kon hy dit nie altyd gemaak het nie; maar at least het hy dit gemaak tot graad elf toe op skool.*
>
> *he went to school né he was very fond of going to school. But because he couldn't read well at school, he couldn't always make it; but at least he made it up to grade eleven at school.*

Lastly, Suzette mentioned that her son and his peers were caught while in the possession of cannabis at school, this ultimately led to his expulsion from school: *"toe was hulle gevang met dagga op die skool, toe word hy geskors" ("then they were caught with dagga at school, then he was expelled")*. This can be considered as problematic behaviour, as Cannabis possession is an illegal act in South Africa (Republic of South Africa Government Gazette,

1992).

Sub-theme 1.3: The biopsychosocial behaviour changes before the onset of schizophrenia. This sub-theme consists of any behaviour change, biologically, psychologically, or socially, in the patient; as it was perceived by the caregiver prior to the diagnosis of schizophrenia. Fundamental to this sub-theme is that caregivers reported that the patient's change in behaviour was viewed as new, odd, and unexpected in comparison to the patient's known behavioural characteristics at the time.

Caregivers reported physical behaviour changes such as weight loss, and social behaviour changes, for example, that patients started imitating others, before the onset of schizophrenia. Caregivers further reported psychological behaviour changes in the person who is now living with schizophrenia. Caregivers reported numerous symptoms common to various mental disorders classified in the DSM-5 (APA, 2013); however, signs and symptoms of Neurodevelopmental disorders, Depressive disorders, Obsessive-compulsive and related disorders, and Neurocognitive disorders (NCDs) were most prominent in the patient before the onset of schizophrenia (APA, 2013). It is important to mention that this does not imply that the patient met the full diagnostic criteria for these mental disorders; simply, patients displayed some symptoms of these alternative mental disorders. Four examples of symptom patterns follow:

First, Charlie was one of two caregivers who reported that his son displayed symptoms of hyperactivity, one of the core symptoms of Attention-deficit/hyperactivity disorder (ADHD) (APA, 2013). Charlie's son's hyperactivity surfaced in "naughty" behaviour at school. Interestingly, at the time Charlie and medical personal suspected that his son may indeed have ADHD. As a result, Charlie initiated commonly used ADHD treatment with his son. Charlie stated during his interview:

> *hy't beginne [pouse] hy't beginne stout raak op skool… en toe, ek dink hy't by toe hy nog jonk ook was het [pouse] hulle vir hom, ek dink daar by daai, rem-, uh [dink] remedial clinic, het hulle vir hom begin Ritalin gee en sulke goed, laat hy, hy't daar begin hyperactive raak. Hy't begin hyperactive raak…*
>
> *he began to [pause] he became naughty at school… and then, I think he when he was young still too he was [pause] they took him, I think there at that rem- uh [thinking] remedial clinic, they began to give him Ritalin and stuff like that, so that he, he started getting hyperactive there. He started getting hyperactive…*

Second, Zuby and Suzette both reported that their children displayed symptoms common to Major Depressive Disorder (APA, 2013) and/or Dysthemia (APA, 2013) as psychological behaviour change prior to the onset of the schizophrenia. Zuby stated:

> *You know, didn't communicate, and talk and didn't want to do anything, didn't want to bath, didn't want to eat, and things like that, he really went deep down, and then he used to break out in his moods, anger, and wander off and don't come back, and things like that.*

Third, Charlie, Olivia, and Zelda reported that their children displayed symptoms of Obsessive-Compulsive Disorder (OCD) (APA, 2013). Here, it was the combination of obsessions and compulsions – and specifically the repeated behaviours that mark the compulsion part of OCD, that were noted by caregivers. Zelda stated how she became aware of her son's repeated behaviour patterns: *"As [hy] die hek oopskuif, dan draai hy weer, maak hy die selle, alles doen hy twee keer oor, even as hy by die pavement afklim." ("When [he] opened the gate, then he would turn again, he does the same, he does everything twice over, even when he gets off the pavement.").* Charlie voiced a similar experience when he told that his son constantly rearranges the furniture in the house: *"hy rearrange als die heeltyd… hy skuif gedurig my bed of hy sit ander gordyne op of hy sit, as ek alles moet skeef wees, ek sê altyd hoekom moet alles skeef wees, alles is skeef." ("he rearranges everything all the time… he often moves my bed or he puts up other curtains or he puts, if I- everything must be skew, I always say why must everything be skew, everything is skew.")*

Fourth, five participants reported that the patient started forgetting experiences and events prior to their diagnosis with schizophrenia. This amnestic state is a core symptom of various NCDs. The interaction between Charlie and me below encapsulated the forgetfulness that his son experienced:

> Divan: *Ek wil nou so bietjie terugspring, jy't vroëer gepraat van die, jy't agtergekom daar's iets fout, kan jy hierdie aanloop tot nou, waar hy nou siek is en gediagnoseer is, of waar hy nou is, kan jy die aanloop miskien 'n bietjie vir my verduidelik hoe jy agtergekom het dat daar iets fout is?*
>
> Charlie: *Ja sy sy…sy vertragings [pouse] soos ek sê sy vergeetagtigheid…*
>
> Divan: *I want to jump back a bit now, earlier you spoke about the, you realised that something was wrong, this build up until now can you, where he is sick now and diagnosed, or where he is now, can you describe the build up to me how you realised*

that something is wrong?

Charlie: *Yes his his… his delays [pause] like I say his forgetfulness…*

Natalie narrated a similar experience when she informed me of her brother's forgetfulness; as he frequently forgot where he placed his belongings. To assist her brother, Natalie offered to keep her brother's belongings with her:

Natalie: *... maar dan vergeet hy ook nog waar hy dit gesit het… Daar was tye wat hy vergeet het, dan vra hy vir my het ek sy ketting.*

Divan: *So hy's vergeet- hy's vergeetagtig ook gewees?*

Natalie: *Vergeetagtig, ja nou nog. Hy weet nie waar hy die goete neersit nie. Nou in die stadium nie… nou gee ek, sê ek vir hom gee die goed vir my, ek sit dit weg. As jy terugkom dan vra jy vir my dan gee ek jou. Maar nou weet ek mos hy gaan sit dit daar neer, maar as hy nou nie geweet het waar hy dit neergesit het wat sou geword het, dan was dit mos nou weer weg.*

Natalie: *... but then he also forgets where he put it…. There were times when he forgot, then he asks me do I have his chain.*

Divan: *So he's forget- he was forgetful too?*

Natalie: *Forgetful, yes now still. He doesn't know where puts stuff. Now in the stage not… now I give him, I tell him give the stuff to me, I'll put it away. When you get back then you ask me then I'll give it to you. But now I know he goes and puts it down there, but now if he didn't know where he put it what would have happened, then it would now be gone again.*

Theme 2: Onset of schizophrenia. The second theme that emerged from the data was that some caregivers experienced the onset of schizophrenia as rapid, and as a result did not expect the diagnosis at the time. Therefore, this theme represents the narratives that introduced this notion of unexpected onset of schizophrenia in the patient.

Cassey reported that her son suddenly became ill with schizophrenia when he was about 28 years of age:

Nee, dit het skielik verander. Dit het skielik verander... so- dis wat hy- wat hy- wat hy die siek... Ja, hy was ook so- Hy was ook so in 28, daarheen rondte... Jy was nie bewus van dit nie en dit was so 'n groot skok.

No, it changed suddenly. It changed suddenly... so- that's what he- what he- that the

illness... Yes he was also like- He was also like that in 28, there around... You weren't aware of it and it was such a big shock.

A similar experience was reported by Suzette: *"Want, kyk, hy was nou- hy was mos nou nog jonk en hy het- hy het mooi geleer in skool, jy sien, hy het mooi geleer in skool en skielik gebeur dit nou." ("Because see, he was now, he was still young and he- he learned well in school, you see, he learned well in school and suddenly it happens.")*

Theme 3: Patients' behaviour after becoming ill. This third theme focuses on caregivers' perceptions of the patient after the schizophrenia diagnosis. During the interviews and later when analysing the data, it became clear that caregivers distinguished between the "person before schizophrenia" and the "person living with schizophrenia". Therefore, this theme encompasses narratives that describe the person who was now living with schizophrenia. This theme can be divided into four sub-themes, which more accurately describes the patients who were being cared for by the caregivers in my study.

Sub-theme 3.1: The easy patient. Caregivers experienced patients as *easy patients* when they reported that it was not a challenge to have the patient living with them, and when they narrated that it was not a difficult task to provide care for their family member with schizophrenia. Several factors seemed to contribute to patients being seen as "easy" by caregivers in my study. Four factors were very common:

Accepting the illness: when the patient realised he/she was ill, this insight contributed to forming an easy patient.

Adherence to treatment: when patients adhered to their antipsychotic treatment regime, caregivers reported that it was easy to care for the person with schizophrenia.

Avoiding substance misuse or abuse: when patients did not engage in drug and substance misuse or abuse, caregivers reported easy patient narratives.

Independence in daily living: patient independence was a fundamental characteristic of easy patients – as the independence alleviated caregivers from various stressors.

Examples of some of these factors are presented next:

Cassey compared her two sons who have been diagnosed with schizophrenia. Throughout the interview her narratives formed a pattern that identified Chris as the "easy patient" and his brother as the "difficult patient". Cassey reflected how her one son, Chris, is aware of his illness and in touch with it: *"Chris is meer 'in tune' met sy siekte as Hilton. Chris besef- hy verstaan dat hy's siek."* (*"Chris is more in tune with his illness than Hilton.*

Chris realises- he understands that he's sick."). Similarly, Zuby's opinion was that her son realised that he was ill and by coming to this insight, he voluntarily admitted himself to Stikland Psychiatric Hospital: *"I think he realised there's something not good going on in him, and then he came to Stikland on his own. I didn't bring him here."*

Furthermore, Doris elaborated that when the person with schizophrenia adhered to their antipsychotic medication, it made life easier for Doris as caregiver: *"Maar Dawn is meer gehoorsaam, sy neem haar ta- as ek weer sien dan't sy haar tablette gedrink en so aan, en het sy haar werkies gedoen." ("But Dawn is more obedient, she takes her- when I see then she's taken her tablets and so on, and she has done her chores.").* Suzette explained how her son's adherence to his medication eliminates his problematic behaviours. It was interesting to hear that, as result from her son's committed medication use, Suzette challenged his diagnosis of schizophrenia. Suzette stated:

> *Kyk, Fred is die een- Fred is baie rustig, ek het nie 'n probleem met Fred. Fred is baie rustig en hy- hy's nie vir my 'n probleem nie. Ek- ek hoef nie vir hom te sê- of hom te- vir hom te onthou, "Het jy al jou pille gedrink," of... of so nie. Somtyds dan voel dit vir my dat Fred het nie skisofrenie nie.*
>
> *Look, Fred is the one- Fred is very calm, I don't have a problem with Fred. Fred is very calm and he- he isn't a problem for me. I- I don't have to tell him- or to- to remind him, "Have you taken your pills yet", or- or like that. Sometimes it feels to me as if Fred doesn't have schizophrenia.*

Sheila expressed her relief that her daughter has never had a relapse – Sheila attributes this to her daughter's abstention from alcohol and cigarette use: *"I'm glad to this point that she's never ever had a relapse [pause] that I thank God, but I think it's because she didn't drink and she didn't she doesn't smoke."* Lastly, Sheila continued to explain how her daughter's independence in daily living made life easier for her as caregiver and how impressed she, as mother, was with her daughter:

> *Oh, she's more positive now, she's [hesitates] how can I say it? [pause] uh… you know she's independent because she used to depend a lot on her daddy there to do her … [pause] 'daddy uh… Now I marvel at her because she does it, even for a booking for this for that, phoning her doctors phoning the medical aid and you know, because that's all things she expected her daddy to do [pause] you know she wanted it but now she's got the confidence to do all that. So I'm happy for that, that she's independent in*

other ways [pause]. She's very independent.

Sub-theme 3.2: The difficult patient. Caregivers experienced patients as *difficult patients* when it was a challenge to provide care for the person with schizophrenia. Moreover, when patients' behaviours introduced challenges at home, caregivers also reported difficult patient experiences. As with easy patients, difficult patients, as reported by caregivers in my study, can be identified by certain reported characteristics. Difficult patients are described by the following traits: the lack of insight about their schizophrenia; non-adherence to their antipsychotic medication; they engage in drug and substance misuse or abuse; patients who stay out late at night; violent patients; individuals who behave oddly; and patients who ignore request from their caregivers. Examples of some of these characteristics are presented below:

First, Sheila mentioned how, at times, her daughter refused to adhere to her antipsychotic medication and Sheila had to bribe her daughter to take her medication: *"But with Shirley there were times when she would take her medication and there was times where she didn't want to take her medication, then I had to bribe her or play along with whatever she was now saying…"* Second, Maryna reflected on the difficulty she experienced when her son swore at night:

Maryna: *Toe sy bel toe's ek baie bly, want toe's dit in die stadium wat hy net begin te weer… [pouse] vir ons begin te…[huiwer] probleme gee*
Divan: *Hmmm, vertel my gou bietjie van die probleme? [aanmoedigend]*
Maryna: *Die probleme was mos nou die vloekery in die nag…*

Maryna: *Then she phoned and I was very happy, because then it was at the stage where he was just starting to… [pause] starting to… [hesitates] give us problems.*
Divan: *Hmmm, tell me briefly a bit about the giving problems? [encouraging]*
Maryna: *The problems were the swearing at night…*

Lastly, Suzette mentioned how it was "baie swaar" (very tough) for her when her son ignored her request or refused to cooperate in the caregiving environment: *"Ja… is baie swaar, baie swaar, ek meen as hy net… saam met ons kan saamwerk, daai's wat ons wil hê, but hy doen nie sy samewerking nie…"("Yes… it's very tough, very tough, I mean if he could… just cooperate with us, that's what we want, but he doesn't give his cooperation…")*

Sub-theme 3.3: Caregivers' reports of a high functioning patient. Schizophrenia takes its toll on a person's psychological and social functioning (Asmal et al., 2014; Esan et al., 2012). Despite this, caregivers experienced that patients were able to maintain certain aspects of their psychological and social functioning after diagnosis. Thus, this sub-theme encapsulates those narratives where caregivers felt, that despite being ill, patients showed ability in various psychological and social functioning domains. Caregivers reported eight properties of *high functioning* patients. Some of these characteristics were intrapersonal properties of the patient, such as: being confident, independent, and self-motivated; the ability to take on responsibilities; the ability to execute daily tasks of living; the ability to further schooling after diagnosis, and the ability to maintain a job. Whereas, other properties of high functioning patients were abilities on levels of interpersonal functioning, such as: the ability to form social relationship, and related to the latter is the ability to form intimate relationships. The eighth characteristic of high functioning was the ability to offer companionship to the caregiver.

Sheila was one of three caregivers that noted self-motivation in the patient after diagnosis. She explained how amazed she was that her daughter's self-motivation was a decisive factor in her ability to further her schooling while living with schizophrenia:

> *She had three more months to go to school and I said leave it! Rather start the year over again but she was very determined that she wanted to finish her studies, she was at Pentech I think, and then I was amazed the end of the year when she got this for [pause] statistics hey? She got nogal a good mark [pause] and because of her determination she would study and I used to think no that's bad for you working the brain like that, you know?*

In his interview, Charlie said that his son has owned a parrot for the past six years. Additionally, his son also owns a dog as pet. In our interaction, Charlie confirmed that he was impressed with his son's commitment to the responsibility of caring for a pet:

> Charlie: *…maar sy papegaai het hy nou ses jaar al.*
>
> Divan: *Hy het daai commitment tot sy papegaai en dat hy vir sy papegaai sorg…*
>
> Charlie: *Ja [besvestigend] en die hond…die hond ook [pouse] die hond is alles vir hom…Weet hy's hy hou van hy's, soos ek sê hy's mal oor diere.*
>
> Charlie: *… but his parrot he has had for six years now.*
>
> Divan: *He has that commitment towards his parrot and he takes care of his parrot…*

> Charlie: *Yes [confirming] and the dog… the dog as well [pause] the dog is everything to him…. Y'know he's he likes he's, as I say he's crazy about animals.*

Moreover, Maryna told about the companionship that her son and his brothers offer her. They offer their companionship by sitting next to her bed at times when she is resting in her room: *"Maar hulle gee my rus ook hoor! En dan kom sit hulle nog daar mooi by my bed ook as ek so lê en lê- ja." ("But they give me rest as well! And then they'll come and sit at my bed when I'm lying and lying- yes.").*

Lastly, Sheila reported that her daughter has, subsequent to her diagnosis with schizophrenia, been married. Her daughter is, furthermore, able to execute daily tasks of living independently for her and her husband:

> *Shirley's fine, she's married… she cooks now and everything for her husband and herself and so, like she says we don't live past each other but they sort of on their own, they do their own thing, they don't have to say we doing this or we doing that they get on with their lives and we get on with ours.*

Sub-theme 3.4: Caregivers' reports of a low functioning patient. Due to the toll that schizophrenia may have on a person's psychological and social functioning (Asmal et al., 2014; Esan et al., 2012), caregivers also realised that patients, after diagnosis, displayed diminished or an entire lack of certain psychological and social functioning skills. Thus, this sub-theme encompasess stories that demonstrate patients' reduced or complete lack of psychological or social abilities, as perceived by caregivers.

Low functioning patients were characterised by reported diminished or lack of ability to: form social relationships – and related to this was caregivers' perception that patients tend to socially isolate themselves significantly after diagnosis; the loss of intimate relationships; the loss of abilities in completing daily tasks of living; inability to hold a job; a poor sense of money's worth – that frequently caused patients to spend money recklessly.

Nine caregivers voiced how they realised that the patient isolated themselves after diagnosis. Social isolation mainly manifested in the form of patients withdrawing to their rooms to avoid interaction with others, may it be friends or family, in the caregiving environment. Charlie reflected how his son isolated himself to his room:

> *Nou all of a sudden, dan sit ek nee jissie, daar's weer 'n [pouse] dan's hy in die kamer die heeltyd of dan sluit hy die deur, of hy's – hy bly in die kamer die heel middag, is hy in die kamer… of in die aand.*

> *Now all of a sudden, then I'm sitting no jissie, there's another [pause] then he's in the room the whole time or he locks the door, or he's- he stays in the room the whole afternoon, he's in the room… or at night.*

While, Suzette reported how her son had lost interest in maintaining relationships with his friends and that he generally did not interact with others during family gatherings:

> *...sy vriende wat hy gehad het, hy worry nie meer met sy vriende wat hy gehad het nie, hy's meer alleen, en as ons- as ons families by mekaar kom of so hy sal nie- hy sal nooit saamgaan nie, of as my familie miskien vir my kom kuier dan sal hy- hy sal maar daar buite sit of so. Hy sal maar net kom groet en dan maar weer uit, en so aan.*

> *...his friends that he had, he doesn't care anymore about his friends that he had, he's more alone, and when our- when our families get together or so he won't- he'll never come along, or if my family maybe visits me then he'll, he'll sit outside there or so. He'll just come and say hello and then leave again, and so on.*

Furthermore, caregivers felt that patients had, since diagnosis, lost their ability to execute daily acts of living. Interestingly, caregivers took responsibility in assisting patients to complete the different daily tasks of living. Two examples of this were; first, that patients regressed to being untidy in their living space: *"Hy is baie onnet- hy's baie onnet, ja. Hy's baie onnet daarin... en dan moet ek daar skoonmaak, ek vee onder die- papier lê, en anders, en die klere lê op die vloer en so aan." ("He is very untidy, yes. He's very untidy with it… and then I have to clean up there, I sweep under the- papers lying, and other things, and the clothes lying on the floor and so on.").* Second, Doris explained how her daughter had regressed and was unable to fulfil some of her basic physiological needs. In response, Doris assisted her daughter with hygiene maintenance, feeding, and medication adherence. Doris explained:

> *Dawn's soos 'n babatjie mos, so sy was iemand- nie meer, hulle's nou nie meer soos iemand wat nou groot is en volwasse nie, dan is hulle soos klein kindertjies wat jy alles moet doen vir hulle. Dan moet jy weer vir hulle voer, jy moet nou vir hulle dink, ek moes vir haar self vir haar gedink het wat sy moet doen. Want in die oggende moet ek vir haar sê kan wakker maak, dan moet ek sorg eerste [pouse], sy moet nou eers vir haar handjies gaan was en haar tande gaan borsel, en dan gee ek vir haar mos vir haar [pouse] hoe sê mens nou, haar breakfast, haar ontbyt. Laat sy eers haar ontbyt*

eet, en dan gee ek haar haar tablette.

Dawn's like a baby, so she was someone- not anymore, they're not like someone who's grown up and mature anymore, then they're like small children that you have to do everything for them. Then you have to feed them again, you have to think for them now, I had to think for her what she had to do. Because in the mornings I have to say be able to wake her up, then I have to first take care of [pause], she first has to go and wash her hands and brush her teeth, and then I give her her [pause] how does one say, her breakfast, her breakfast. Let her first eat her breakfast, and then I give her her tablets.

Lastly, three caregivers stated that, since being diagnosed, the patient had loss his/her ability to handle money responsibly. Natalie reflected how her brother had recklessly spent all his money and that he ended with no money for future use:

...hy gaan dit betaal anyway want hy budget dan nie sy sy limits nie sy limits is 'n high. Okay hy betaal sy skuld daai one thing for sure, but dan het hy niks for homself oor by die einde van die dag.

... he's going to pay it anyway because he doesn't budget his limits, his limits are high. Okay he pays his debt that one thing's for sure, but then he doesn't have anything left for himseld at the end of the day.

Zelda told me that her son had sold her husband's expensive hardware equipment for a minuscule amount in order to feed his drug use habit: *"Hy't nie, hy't nie worry nie, wat hy verkoop verkoop hy. Ek het gisteraand gehoor hy't sy pa se drill verkoop vir R60." ("He doesn't, he doesn't have a worry, what he sells he sells. I heard last night that he sold his dad's drill for R60.")*

Theme 4: Caregivers' observations of the effects of patient's medication use. The fourth theme related to caregivers' perception of the patient, was perceptions of persons with schizophrenia's medication use. This theme specifically explores caregivers' perceptions of patients' antipsychotic medication use, and the effects that medication use had on the patient. Two sub-themes emerged that represent caregivers' stories. The first sub-theme is: side effects of antipsychotic medication, whereas the second sub-theme is unresponsive to antipsychotic medication. The respective sub-themes are presented below:

Sub-theme 4.1: Side effects of antipsychotic medication. This sub-theme includes the reported side effects of antipsychotic medication that caregivers observed in patients who were being cared for. Side effects included decreased libido, diminished immune function headaches, hyperactivity, and insomnia. However, when measured against the entire data set, narratives were predominantly marked by three side effects of antipsychotic medication on the patient, namely fatigue, excessive sleep, and increased appetite.

Six participants reported their observations of medication side effects. Suzette stated that her son is easily fatigued since using antipsychotic medication: *"Dis nou net die medikasie wat hy gebruik, hy raak baie gou moeg." ("That's just the medication that he uses, he gets tired very quickly.").* Zelda informed me that the excessive sleeping of her son introduced its own, additional challenges: *"Daai pille laat vir hulle heeldag baie slaap. Dit laat vir hulle baie slaap. En toe's dit ook nou 'n probleem." ("Those pills make them sleep a lot the whole day. And that is a problem now as well.").* Zelda, further elaborated on her son's increased appetite when medication is used:

> Zelda: *En, nog 'n ding, Mark het altyd…die chips, sy tasse het chips wat jy koop by die winkeltjie, altyd 'n klomp chips vir hom lekkers, hulle hou van soet goed, lekkers, sigaret.*
>
> Divan: *Eet hulle?*
>
> Zelda: *Chips. En as hy die punte kry wat hy kry, ek weet nou nie wat's die punt se naam nie. Hy eet geweldig. In daai tyd wat hulle…eet, daai pille gebruik, eet hulle en hulle gewig tel sommer spoed op.*

> Zelda: *And, another thing, Mark always has… the chips, his bags have chips that you buy at the shop, always a bunch of chips for him, sweet, they like sweet stuff, sweets, a cigarette.*
>
> Divan: *They eat?*
>
> Zelda: *Chips. And when he gets the points that he gets, I don't know what the name of the points is. He eats enormously. In that time which they… eat, drink those pills, they eat and their weight picks up quickly.*

Sub-theme 4.2: Unresponsive to antipsychotic medication. The second sub-theme that describes caregivers' observations of patients' medication use encompasses narratives that illustrate that at times the antipsychotic medication had no effect on the user. Stated otherwise, the person did not react to the treatment. As a result, patients' psychotic

symptoms are not alleviated after medication use.

Doris' narrative summarises this sub-theme when she explains how her daughter did not respond, as expected, to various antipsychotic medications:

> *sy was nou hoeveel keer al op daai wonder inspuiting, sy't mos hier gewees sy't nou elke tweede, die tablette het sy nou elke tweede week gekom het, ja, elke twee weke vir die inspuiting, en toe's dit nou weer maandeliks. Sy was nou vir drie jaar mos…dan werk dit het nie op haar gewerk nie. Toe raak dit weer toe raak sy weer so sy't aan die begin geraak… siek geraak het.*
>
> *she's now been on that miracle injection how many times, she was here she was every second, the tablets she came for every week, yes, every two weeks for the injection, and then it was monthly. She has been for three years now… then it didn't work on her. Then it became she became like at the beginning, became sick.*

Theme 5: Recovery enabling factors. The fifth theme that reports caregivers' perceptions of the patient is *recovery enabling factors*. This theme includes various factors that, according to caregivers in my study, promoted the well-being or recovery of patients who live with schizophrenia.

Caregivers reported four factors that facilitated recovery in individuals with schizophrenia. The first and most frequently coded quotations identified antipsychotic medication use as the most influential enabler of the recovery process. Second, mental healthcare services played a fundamental role in enhancing the psychological well-being of individuals with schizophrenia. Here, psychologists and psychiatrists were key contributors to this process. Third, patients who engaged in social interactions also tended to show signs of improved well-being. Lastly, religious factors also played a complementary role in recovery.

Betty attributed her son's improved well-being to the medication that he was prescribed with:

> Divan: *Hoekom dink jy hy het reggekom?*
>
> Betty: *Die pille miskien wat hulle hom gegee het, want dis mos different tipe pille as wat hulle altyd gegee het, wat hulle hom- te sê, wat hom gaan gekry het en so aan. Different- different pills.*
>
> Divan: *Why do you think he got better?*
>
> Betty: *The pills maybe that they gave him, because it's a different type of pills than*

they always gave him, that they- say, that got him and so on. Different- different pills.

Zuby explained how a psychiatrist who worked on the Shared Roots Project played a key role in getting her son on schizophrenia-treatment regimes:

Zuby: *I mean, we've had Dr. X and them also treating. When I came here the first time Dr. X saw him, the two of us, and she started her research with him. And that's when it really started off, that he got treatment, or medication and things like that, and then eventually it came down to this point where he only gets the injection twice a week.*

Divan: *Mm hm. Twice a week?*

Zuby: *No, once every two weeks.*

Lastly, Betty also stated that since her son started interacting with others, she noticed improvement of his well-being: *"Toe- Brett is ń stil mens, dan was hy baie stil gewees en hy het weer begin meng met mense, en vandat hy gemeng het meer met mense het hy reggekom en reggekom." ("When- Brett is a quiet person, then he was very quiet and he began to mix more with people, and since he mixed more with people, he became better and better.")*

Theme 6: Recovery hindering factors. The last theme that emerged, explaining caregivers' perceptions of the patient, was *recovery hindering factors*. This theme encompasess various factors that, according to caregivers in my study, hampered or prevented the person with schizophrenia from obtaining optimal well-being or recovery while living with schizophrenia.

Caregivers identified five recovery hindering factors. The first and most prominent recovery hindering factor was drug and substance misuse or abuse by the patient after diagnosis. Second, patients who isolated themselves tended to show lower signs of improved well-being. Third, a passive lifestyle also hindered recovery in persons with schizophrenia. Lastly, it was interesting to hear that caregivers regarded nagging as a recovery hindering factor. Caregivers felt that when they nagged patients about events or requests, recovery was obstructed.

Olivia stated how her son's cannabis use prevents the proper functioning of the antipsychotic medication. She further stated, when her son adheres to his medication, he is the "lieflikste" (loveliest) child. Our interaction is presented below:

Olivia: *Hy mag'ie… hy mag'ie want die medikasie wat hy kry dit werk nie saam met daai nie.*

Divan: *Rook nie? [bevestigend]*
Olivia: *Ja, maar hy mag'ie eintlik rook nie. As hy gaan rook het en hy kry sy medikasie, dan is dit nog altyd dieselle, maar as hy nie gaan rook het nie met sy medikasie dan is hy die lieflikste kind wat jy kan kry.*

Olivia: *He's not allowed… he's not allowed because the medication that he gets doesn't work with that.*
Divan: *Doesn't smoke [confirming]*
Olivia: *Yes, but he isn't actually allowed to smoke. If he's smoked and he gets his medication, then it's still the same, but if he hasn't smoked with his medication then he is the loveliest child that you could get.*

Moreover, Zelda felt that her son's passive lifestyle prevented his recovery, as it introduced temptations for him to engage in problematic behaviour:

En, aan die begin as ek, as hulle uit die hospitaal uit kom, en hulle's by die huis en hulle moet nou pille, daai ledigheid, daai tyd ledigheid, hy, hulle moet sommer gaat werk, hulle moenie nog by die huis lê nie. Hulle moet die pille drink, fine en die aand en gaan slaap maar hulle moet soos normaal aangaan more want ledigheid is die duiwel se oorkussing want hulle't te veel, especially in onse areas.

And, in the beginning when I, when they came out of the hospital, and they're at home and they must pills, that laziness, that time laziness, he, they must go and work, they mustn't lie around at home. They must drink the pills, fine and the night and go to sleep but they must carry on normally tomorrow because laziness is the devil's pillow because they have too much, especially in our areas.

Zelda continued as she warned others – those caregivers who nag the patient – this may contribute to a significant decrease in the person with schizophrenia's well-being. Zelda feels that the effects of the nagging is so detrimental to the patient, that it may lead to their admission to psychiatric care centres such as Stikland Psychiatric Hospital:

As jy nie jou kind weer daai kant wil hê in Stikland of dinge laat doen nie, moenie nag nie. Treat them well, treat them ordentlik soos jy wil ge treat word. Ek sê, nee ek het ook, moenie op sy kop nag nie.

> *If you don't want your child on that side in Stikland or let him do things, don't nag. Treat them well, treat them properly like you would like to be treated. I say, no I also have, don't nag on his head.*

Caregiver Burden

This section describes the experiences of caregiver burden as reported by participants, and burden was conceptualised through the Objective and Subjective Burden framework that has been introduced in Chapter Two. The respective themes and sub-themes derived during TA are summarised in Table 3.

Table 3

Themes and Related Sub-themes Related to Caregivers' Experiences of Caregiver Burden

Caregiver Burden			
Theme family 1: Caregiver's contextual challenges			
Theme 1	Day-to-day circumstantial challenges		
Sub-themes (1.1-1.9)	Socio-environmental challenges	Caregiver's age	Additional health challenges
	Being the only caregiver	Caring for more than one patient with schizophrenia	Caregiver's lack of knowledge of schizophrenia
	Lack of social support for caregiver	Caregiver's personal life burdens (past, present, future)	
Theme family 2: Burden directly introduced by having patient live at home			
Theme 2	New experiences witnessed		
Sub-themes (2.1-2.4)	Illness related behaviours	Patient's problematic behaviour	Distressing experiences caused by having the illness
	Patient abused by community members		
Theme 3	The effect on the caregiver's social environment		
Theme 4	Emotional impact on caregiver		
Sub-themes (4.1-4.2)	During diagnosis	Continuous caregiving over a long period	
Theme 5	Patient dependency		
Theme 6	Living with a sense of obligation to care		
Theme family 3: Burden introduced as result of providing care			
Theme 7	New activities for caregiver		
Theme 8	Physical strain on caregiver		
Theme 9	Disruption		
Theme 10	Difficulties experienced at healthcare services		

Before reporting the themes and sub-themes that were derived from TA, I need to mention that all themes in this section could fit into one of three theme families (i.e., overarching themes). A theme family may be described as an overarching description of the themes that it comprises of. All themes and sub-themes found in a theme family can be viewed as building blocks of that particular theme family. This also suggests that the themes and sub-themes found in a theme family may, ultimately, be related or interconnected with another.

To maintain a uniform structural layout of this chapter, I define and discuss each theme family in the next three paragraphs. Thereafter, the respective themes and sub-themes are discussed under their respective headings.

The first theme family – *the caregiver's contextual challenges*, can be defined as the challenges that caregivers experienced apart from the challenges that are introduced when having to provide care for the person with schizophrenia at home. These challenges may be caused by external community and societal factors, which caregivers have little or no control over (Bronfenbrenner, 1979). It also encompasses challenges that may have been experienced even if caregivers were not caring for a person living with schizophrenia. After analysis, one theme emerged from the data set: *Day-to-day circumstantial challenges*.

The second theme family – *burden directly introduced by having patient live at home*, represents the burdens that are introduced by having the person living at home after diagnosis. This implies that if the patient were to have been permanently institutionalised after diagnosis, these challenges might not have been experienced by the caregiver. Five themes emerged as members of the second theme family: *new experiences witnessed*; *the effect on the caregiver's social environment*; *emotional impact on caregiver*; *patient dependency*; *living with a sense of obligation to care*.

Lastly, the third theme family – *burden introduced as result of providing care*, can be defined as the burdens that are consequences from carers' caregiving acts and role. Corresponding with the second theme family, these challenges might not have been experienced by caregivers if the patient were permanently institutionalised after their schizophrenia diagnosis. Four themes emerged and formed part of this theme family: *new physical for caregiver*; *physical strain on caregiver*; *disruption*; *difficulties experienced at healthcare services*.

Theme 1: Day-to-day circumstantial challenges. This theme includes challenges that are experienced by caregivers on a daily basis. What differentiates this theme from other challenges are the notions of consistency and continuity that characterise these experiences; where other challenges may be periodic or come and go; day-to-day challenges may be

considered as ever present. Day-to-day challenges can be further divided into eight sub-themes that illustrate these challenges more independently.

Sub-theme 1.1: Socio-environmental challenges. This sub-theme represents various challenges that caregivers experience in and around the immediate caregiving environment. These challenges, however, are not directly caused by the person who lives with schizophrenia. Socio-environmental challenges which caregivers experienced included: conflict with their neighbours, gangsterism in the community; racism, and vandalism. However, one socio-environmental challenge appeared common in caregivers' narratives – the struggle with drugs in the community.

Betty was one of six caregivers who voiced her concern about drugs and the easy access to it in the community. Caregivers like Betty felt that drug use facilitates the development of schizophrenia in individuals, while she also stated that her son does not use drugs:

> *...want ek- ek meen maar- want baie van die ouens dink hierdie skisofrenie kom van drugs af, die meerderheid, die meerderheid, want ek sien elke dag in onse dorp hoe gaan dit daar, en my kind is nie ń drinker nie, hy's nie ń roker nie.*
>
> *... because I- I mean- because many of these guys think that this schizophrenia comes from drugs, or the majority, the majority, because everyday I see how it goes in our town, and my child is not a drinker, he's not a smoker.*

Sub-theme 1.2: Caregiver's age. This sub-theme refers to narratives where the caregivers discussed their age as a life difficulty. Caregivers felt that, not only is old-age a life difficulty, it is a major barrier to schizophrenia-caregiving.

Six caregivers reported that their age made it difficult for them to provide care for the patient. Also, caregivers expressed that old-age introduced a sense of mental or emotional fatigue. Two examples of this were provided by Charlie and Sheila:
"ek is nou, ek raak te oud daarvoor, ek kan nie meer byhou nie…" (Charlie) (*"I am now, I am getting too old for this, I can't keep up anymore…")* (Charlie); and,

> *"you know at night he would open the doors there and [pause] my husband said there's he going out again man… so that was already traumatic for me and as parents it was in our, we're not young anymore to deal with this and now you doing all this to us…"* (Sheila)

Sub-theme 1.3: Additional health challenges. Apart from the challenges that are introduced when caring for a person with schizophrenia, caregivers also reported other physical and mental health difficulties that made their life more difficult on a day-to-day basis. Interestingly, both the caregivers' and the patients' health related problems added to the complexities associated with the burden of caregiving.

Nine caregivers experienced personal health difficulties, which introduced their own unique challenges. Skollie reported that he had an underactive thyroid gland and was on treatment for this: *"ek het- ek het onder aktiewe skildklier, ek is op Eltroxin een en 'n half pille deesdae, in die dag." ("I have, I have an underactive thyroid, I am on Eltroxin one and a half pills nowadays, during the day."*) Charlie stated that he was living with diabetes and also needed medication to regulate his blood glucose levels:

> Charlie*: …en dan vat ek die Glucofane in die aand… vir my, vir my suiker, maar want dan kan ek my suiker reguleer… hulle sê dis die skok wat ek gekry het want ek het nooit suiker gehad nie.*
>
> Divan: *Ek neem aan jy's 'n diabeet?*
>
> Charlie: *Ja*

> Charlie: *… and then I take the Glucofane at night… for my, for my sugar, but because then I can regulate my sugar… they say it's the shock that I got because I never had sugar.*
>
> Divan: *I assume you're diabetic?*
>
> Charlie: *Yes*

Zelda explained that she was on treatment for depression: *"en darem gebruik ek nou die pille, ek wat's dit? Wat's die naam, Epsom Plus, depressie goed is. Ek het daai pille … Epsom Plus, daai ek het was gesond, nou moet ek daai pille drink." ("and at least I use the pills now, I, what is it? What's the name, Epsom Plus, depression stuff. I have those pills… Epsom Plus, those I have to, I was healthy, now I have to drink those pills.")*

Five caregivers narrated that the patient, apart from having schizophrenia, also had other health problems. Sheila expressed how she had argued with her daughter. It appears that the argument evolved due to the fact that her daughter who has diabetes, does not follow a diabetes-friendly diet: *"No you don't control your diabetes, you eat and do what you want… you need to be in a place where you've got structure"*. Cassey furthermore reported that her son was displaying symptoms common to diabetes – high blood pressure and high

cholesterol: *"Chris se gesondheid, Chris se bloed is baie hoog en sy kolesterol is baie hoog". ("Chris' health, Chris' blood is very high and his cholesterol is very high".)*

Sub-theme 1.4: Being the only caregiver. Caregivers also experienced the times during which they were the sole caregiver for the patient as challenging. Thus, this sub-theme represents the narratives that illustrated the difficulty by sole caring.

Five caregivers stated that being the only caregiver made life difficult for them. Two male participants, Skollie and Charlie, reflected how they, at times, had no idea what was going on at home and in the lives of other family members – their wives mainly dealt with the caregiving responsibilities.

Zuby expressed how various life demands accumulated, and contributed to making general life and caregiving difficult for her: *"okay, me working all the time, you know, I'm a single parent, I'm divorced, and it was a bit heavy on me because we moved to Cape Town- we're from Port Elizabeth, we moved to Cape Town"*. Similarly, Natalie reported that it was difficult for her when she was the sole carer for her brother during the day: *"vir my was dit moeilik want ek moes alleen met hom in die dag in gesit het". ("it was difficult for me because I alone had to stay with him during the day".).* Lastly, Maryna narrated that, for her, it was unpleasant to raise her children alone: *"ek moes hulle alleen groot gemaak het… [pouse] en dit was nie lekker dae nie, dit was nie lekker dae nie…". ("I had to raise them by myself… [pause] it wasn't good days, it wasn't good days…").*

Early in his interview Skollie mentioned that his wife, Sheila, might be able to share detailed experiences of being a caregiver of a person with schizophrenia. He attributes this to the fact that, in the past, he had spent a lot of time at work, which made him unaware of the happenings in the caregiving environment: *"soos ek sê die vrou sal vir u eintlik meer- meer... Jy weet ek- soos ek sê, ek kom huis toe... ek gaan werk toe. Ek weet nie wat daar aangaan nie. ("as I say the woman will actually be able to more- more… You know I, like I say, I come home… I go to work… I don't know what goes on there.").*

Sub-theme 1.5: Caring for more than one patient with schizophrenia. Caregivers felt that their caregiver burden was exacerbated by caring for or having another patient with schizophrenia at home.

It appeared that at least five participants were currently caring for more than one person with schizophrenia, or had done so in the past. Two mothers of patients with schizophrenia expressed their sense of guilt or shame related to having more than one child with this mental disorder. First, Sheila explained how she had expected Shirley's schizophrenia diagnosis after Sheila's son was diagnosed with it a while before:

And anyway we went straight away through but then we already knew that must be schizophrenia… because the psychologist here at Stikland that saw my son [pause] she said to me one day don't be surprised if another family member gets it too [pause] and I didn't want to tell my husband this 'cause I thought that'll be very …

Second, Doris felt that she and her husband had sinned and as result she gave birth to three children who were ill:

My anders kinders het dit ook [pouse] ek het vir my man gevra wat het ons gesondig? Dat al drie my kinders, eerste vir David… En dan my dogter, die oudste ene, Louisa, ons was hier gewees. Sy sou mos ook in die studie ingekom het hier… ek kan haar nie hanteer nie… kan ek nou praat oor, dis nie Dawn nie?

My other children also have it [pause] I asked my husband what have we sinned? That all three of my children, first David… And then my daughter, the eldest one, Louisa, we were here. She would also have been part of the study here… I can't deal with her… can I talk about, it's not Dawn?

Sub-theme 1.6: Caregiver's lack of knowledge of schizophrenia. Another day-to-day challenge experienced by caregivers was their lack of knowledge of schizophrenia.

It appeared that this lack of knowledge introduced different experiences to different caregivers. Some caregivers were seeking explanations for the onset of, and the symptoms that accompany schizophrenia. Another caregiver felt that it was a curse that was put on their family. Lastly, the lack of knowledge about schizophrenia introduced a sense of uncertainty to caregivers. Examples of caregivers' lack of knowledge about the disorder are presented below:

Skollie expressed his lack of knowledge and need to come to a better understanding of the onset of schizophrenia:

Wie weet? Ek weet nie. Ons weet nie, dis ǹ donker boek, dis ǹ geslote boek... But now, Don, isn't this thing coming from there then? I'm trying to figure it out. Where the hell does this damn thing come from?"

Who knows? I don't know. We don't know, it's a dark book, it's a locked book… But now, Don, isn't this thing coming from there then? I'm trying to figure it out. Where the hell does this damn thing come from?"

Zuby also voiced that she did not understand the illness and what it implies: *"I- I- I don't know how I handled it, but it's- something just came over me that I took control, but I didn't understand the meaning of schizophrenia".*

Sub-theme 1.7: Lack of social support for caregiver. This was the seventh sub-theme that emerged from the data set. Caregivers experienced minimal or a lack of social support from family members and friends outside the caregiving environment. Lack of social support, for purposes of this sub-theme, is created by two factors: 1) others' lack of support towards the caregiver, and 2) caregivers' lack of outreach towards others outside the caregiving environment.

Three caregivers reported lack of social support. First, Maryna stated how she had chosen not to reach out to other family members, as she felt that by letting others into her life would introduce additional challenges: *"Ek het nooit ander mense ingetrek of families nie, want somtyds lyk dit families gee jou net meer probleme…[pouse] soos dit by my kant lyk!"* (*"I never involved other people or families, because sometimes it seems that families just give you more problems… [pause] as it seems on my side!")*.

Olivia reflected how her husband and she had minimal support for a period of six years. She later added that her family talked about her son, but that they did not offer assistance or support:

Divan: *En as ek vra het jy ondersteuning van familie of vriende?*

Olivia: *... Nie eintlik nie, nie eintlik nie… nie eintlik nie, ek maar alleen laat gaan…*

Divan: *So hulle staan jou nie by met Alfred baie nie?*

Olivia: *Hulle's nie happy wat hy doen nie… maar ek sê daar's baie mense se kinders wat die worse dinge aandoen. Worse wat hulle aandoen… but ek sal maar net bid laat hy moet reg moet kom. Dis al wat ons kan doen…*

Divan: *And if I ask have you got support from family and friends?*

Olivia: *... Not really, not really… not really, I alone letting it go…*

Divan: *So they don't support you with Alfred much?*

Olivia: *They aren't happy with what he does… but I say there are lots of people's children who do worse things. Worse things that they do… but I will just pray that he gets better. That's all that we can do…*

She continued: *"…dis swaar is, is baie swaar. Familie sal nie weet wat ek deurgaan nie. Hulle kan net lekker praat, maar hulle help nie. Hulle help nie". ("…it's tough it is, it's very*

tough. Family won't know what I'm going through. They can just talk nicely, but that doesn't help. They don't help".).

Sub-theme 1.8: Caregiver's personal life burdens (past, present, future). This is the last sub-theme that emerged under caregivers' day-to-day challenges. It includes challenging experiences that were not caused by being a caregiver of a person with schizophrenia. Furthermore, these life difficulties, as narrated by participants, may be past, present, or future orientated. While these experiences were not directly caused by, or as a result of, interactions with the patient; these burdens may act as additional stressors in the caregiver's life and to the caregiving environment.

Various personal life burdens emerged during the interviews and it seemed as if many caregivers utilised the research environment to discuss these struggles in the confidential space and to unburden themselves. Some caregivers spoke about their abusive relationships or marriages, divorces, and being raped at a young age. One caregiver emotionally discussed his stillborn child; other participants experienced grief as a result of their loved ones' death. One caregiver also informed me about careers that they always wanted, but that it was not in their destiny to attain the specific career. Examples of caregivers' personal life burdens are presented below:

Cassey informed me about the emotional and physical abuse she experienced in her first marriage:

> Cassey: *Hy- hy was verskriklike jaloers, en hy het met my baklei en hy het my geslaan...*
>
> Divan: *Die man?*
>
> Cassey: *Ja. Die man, ja. Hy was verskriklik jaloers vir my, en daar's afgeknou en geslap en goeters, en- en soort van- ek- ek kon nie eers- ek kon nie eers na my ma toe gegaan het nie (4 sekondes pouse). Ek kon nie eers baie na my ma toe gaan, hy- hy wil my weggehou het van my ma af heeltyd.*
>
> Cassey: *He- he was incredibly jealous, and he fought with me and he hit me…*
>
> Divan: *The husband?*
>
> Cassey: *Yes. The husband, yes. He was incredibly jealous for me, and there was bullying and slapping and stuff, and- and sort of- I- I couldn't even- I couldn't even go to my mom (4 seconds pause). I couldn't even go to my mom often, he- he wanted to keep me away from my mom all the time.*

Skollie, in an emotional discussion, informed me about Sheila and his stillborn son and the immense sadness and disappointment he had experienced because of this:

> *Ek se nou "Okay, ek het nou my seun, al een wat ek het, ek dit was langer, en ek het die een verloor en ek was baie upset, ek het gehuil. Hy was stillborn en die vroedvrou se "Wag, wag, wag, moenie loop nie. Hier's nog 'n ene op die pad." Hy is stillborn nogal, identies. My vrou was off her head. Ek sê jy is so off your head, ek voel dit soos 'n swaard teen my hart, maar soos ek sê al die teleurstellings omtrent dit, ek moes leer om vrede te maak.*
>
> *I say, "Okay, I have my son now, the only one that I have, I, it was longer, and I lost the one and I was very upset, I cried. He was stillborn and the nurse said "Wait, wait, wait, don't leave. Here's another one on the way." He is stillborn indeed, identical. My wife was off her head. I said you are so off your head, I feel it like a sword against my heart, but as I say all the disappointments around that, I had to learn to make peace.*

Lastly, Charlie was, at the time of his interview, still mourning the sudden death of his wife. He longed for her company:

> *Uh [dink] hoe kan ek sê? [pouse] ek raak [pouse] ek raak mismoedig… ek lê daarso, ek mis my vrou, ek, veral in die aande… en dan dink ek by myself, jis, nou ek hier lê [pouse], ten minste het ek iemand om mee te gesels…wat ek nie het nie, nou lees ek 'n boek of ek kyk TV… dit is, dis nie vir my [pouse] ek soek nie 'n ander vrou nie, definitief nie, en daar's niemand wat haar plek kan vat nie… maar baie mense sê vir my jy moet aangaan met jou lewe.*
>
> *Uh [thinking] how can I say? [pause] I become [pause] I become discouraged… I lie there, I miss my wife, I, especially at night… and then I think to myself, jis, now I'm lying here [pause], at least I have someone to talk to… what I don't have, now I read a book or I watch TV… it is, for me it's not [pause] I don't want another woman, definitely not, and there's no-one that can take her place… but many people tell me you must go on with your life.*

Theme 2: New experiences witnessed. This theme encompasses various new experiences that are introduced by having the patient live at home after their diagnosis. It represents caregivers' perceived challenges that might not have been experienced if patients

were not living with their respective caregivers. Furthermore, it should be noted that this theme includes experiences that may have been introduced by patients themselves or others in or in close proximity to the caregiving environment (for example friends and family or members in the community). This theme consists of four subthemes that focus on different novel experiences that caregivers perceived.

Sub-theme 2.1: Illness related behaviours. This sub-theme encompasses reports of various experiences that caregivers encountered as result of the schizophrenia diagnosis and behaviours that characterise individuals with schizophrenia.

Caregivers perceived a number of illness-related behaviours in patients. Symptoms of psychotic episodes such as hallucinations, and delusions (APA, 2013) were among the most common reported. However, caregivers also stated that patients behave oddly, display poor concentration, and tended to be untidy.

Jack was one of seven caregivers who witnessed hallucinations in his girlfriend. He became aware of Jessica's auditory hallucinations, however, his lack of knowledge about schizophrenia left him uncertain of the happenings. He stated: *"I noticed she just- when you talk to her she going to say there's someone who's talking before you, but you were not talking, so I don't know how can I- can I explain it, I don't know".* Similarly, Doris reflected how her daughter had an immense fear for the content introduced by the hallucinations. This also disrupted Doris' sleep pattern. She stated: *"ek was elke dag, mens slaap nie in die nag nie [pouse] want dan is sy vreesbevange [pouse] was sy vrees- sy sê dis die mense hulle jaag vir haar en dan sien sy en sy hoor stemme en [pouse]". ("Everyday I was, you don't sleep at night [pause] because then she is fearful [pause] she was fear- she says it's the people they chase her and then she sees and she hears voices and [pause]".).*

Furthermore, five caregivers reported that patients behaved oddly. This commonly resulted in an uncertain or confused caregiver. Skollie and Sheila's accounts provide evidence to this:

> *Jy weet die ouers sê "Ek sien my kind gaan by die voordeur uit, maar as hy terug kom, ons weet nie wat kom terug nie" jy weet… Wel, dit is nou as ŉ kind nou by ŉ ouer voordeur uitstap, en dan kom die kind weer terug, middernag of môreoggend, maar jy weet nie wat kom nou terug nie. Hy is heelwat ŉ ander mens, jy weet, heelwat ŉ moeilik.* (Skollie)

> *You know the parents say "I see my child going out the front door, but when he comes back, we don't know what comes back" you know… Well, that is if a child walks out*

> *of a parent's front door, and then the child returns, midnight or tomorrow morning, but you don't know what is returning now. He is a very different person, you know, a very difficult.* (Skollie)

Also, Sheila stated how Shirley would one moment ask her to sleep beside her, and the next moment Shirley would chase Sheila out of her bed: *"Because it was terrible [pauses] when she became ill, that … [pauses] she'd tell, 'Mommy come sleep by me' and here you'd think it's nice! And in the middle of the night [chuckles] 'Get out! Get out!"*

Charlie stated that his son was unable to hold down a job, and he attributes this to Conrad's inability to concentrate: *"op sy ouderdom moes hy al lankal gewerk het en hy moes… hy gaan hy't werke gehad wat, hy kan dit nie hou nie, sy konsentrasie daar nie…". ("at his age he should have been working long ago and he should have… he goes he had jobs that, he can't keep it, his concentration isn't there…").* Cassey also explained how her son was unable to concentrate, and as a result, received speed fines while driving his employer's vehicle, consequently being discharged from his job. She stated:

> *Hy het baie traffic fines gekry het deurdat hy nie kan lekker ge-concentrate en- en ek is toe bly hy het tot daardie- daardie dingus gekry, 'n soort van 'n- ook 'n- 'n relapse gekry, en toe het hulle vir hom ge-sack.*
>
> *He got lots of traffic fines because he can't concentrate and- and I was glad that he got to that- got that thing, a type of- also a- a relapse he had, and then they sacked him.*

Lastly, Zelda experienced her son's room as untidy and that it was marked by litter on the ground: *"Hy sal miskien- soos byvoorbeeld jy is byvoorbeeld jy's so besig om jou huis skoon te maak, 'Mark maak jy jou kamer skoon?' Dan kom jy nou in sy kamer dan lê die vullis daar…" ("He will maybe- like for example you are for example you're now busy cleaning your house, 'Mark are you cleaning your room?' Then you come into his room then the rubbish is lying around there…").*

Sub-theme 2.2: Patient's problematic behaviour. This sub-theme includes a number of problematic behaviours which caregivers encounter by having the relative at home. In essence, behaviours of relatives may overlap with behaviours that characterise persons with *Disruptive, Impulse-control and Conduct Disorders* (APA, 2013) or could be secondary to schizophrenia. Therefore, fundamental to this sub-theme is caregivers' reports that indicated

instances where patients' behaviour violated "the rights of others (e.g., aggression, destruction of property) and/or that bring the individual [patient] into significant conflict" with others at home (APA, 2013, p. 461).

Caregivers experienced two main patterns of patients' problematic behaviour. First, patients displayed aggression – this included physical and verbal aggression. Aggression usually preceded patient violent behaviour. Second, patients also engaged in destructive behaviours. Destructive behaviour can be viewed as behaviour inclined to caused harm or destroy property. Acts of stealing from the caregiver and the throwing away of caregivers' property were also viewed as destructive.

Charlie was one of six caregivers who informed me about the patient's aggressive behaviour at home. In his case, his son became aggressive at times when he did not get his way: *"Hoe kan sê, goed wat hy wil hê, en hy kry dit nie dan raak hy kwaad dan raak hy aggressief, dan dis asof hy 'n stryery begin, dan loop ek net weg [pouse] dan loop ek weg". ("How can say, stuff that he wants, and he doesn't get it then he gets angry then he gets aggressive, then it's as if he starts an argument, then I just walk away [pause] then I walk away".).*

Zelda also explained about her son's aggression. She recognised this aggressive behaviour as being drug-induced:

> Zelda: *Die klong is nou aggressive hierso… Toe laat hulle sy pee toets, toe's sy pee so swart soos Coke van die drugs.*
>
> Divan: *Sjoe [empatiek]*
>
> Zelda: *Toe sê hulle 'Meneer, as die kind nie nou hier gekom het nie, by Vrydag was die kind se liggaam […] net 'n lyk. 'n Halfuur daarna toe's die kind nog altyd aggressive, die kind wil nie slaap nie hy, daai medikasie maak hom niks nie, die securities moet vir hom vashou.*
>
> Zelda: *The klong is aggressive here now… then they had his pee tested, then his pee was black like Coke from all the drugs.*
>
> Divan: *Sjoe [empathetically]*
>
> Zelda: *Then they said "Sir, if the child didn't come here now, by Friday the child's body would've been a corpse […] just a corpse. 'n Half hour afterwards, the child was still aggressive, the child doesn't want to sleep he, that medication does nothing to him, the securities have to hold him back.*

Natalie, on multiple instances, referred to Brett's verbal aggression at home. One example follows where he shouted on others at home:

Divan: *En wat skree hy toe?*

Natalie: *'Nee, julle kan nie vir my fokken', hy vloek so, maar nou sê hy dit nie, en 'ek gaan mos nou kyk en die en die' skree hy vir hulle, vloek hy.*

Divan: *And what did he shout then?*

Natalie: *"No, you can't fuckin' make me" he swears like that, but now he doesn't say it, and "I am going to go and see now and this and this" he shouts at them, he swears.*

Six caregivers reported destructive behaviours. In her interview, Cassey told me how her son destroyed their carport:

Cassey: *Toe kap hy- hy het- die carport se pale het hy begin uitkap, uitkap, uitkap. Hy het 'n byl gevat en hy kap en- en hy kap die goeters uit.*

Divan: *Het hy dit afgebreek, begin afbreek?*

Cassey: *Uit, uit, hy breek dit af, hy breek dit af!*

Cassey: *Then he chopped- he had- the carport's posts he started to chop, chop, chop. He took an axe and he chops and- and he chops the stuff out.*

Divan: *Did he break it down, start to break it down?*

Cassey: *Out, out, he breaks it down, he breaks it down!*

Olivia told me about a similar experience to that of Cassey. She reported how Alfred damaged the door and window at home:

Divan: *Ek wonder nou net sommer, as jy hom los, en dit nie sou doen vir hom nie, wat sou gebeur of wat het al gebeur?*

Olivia: *Dan lê hy net heeldag of as hy kom, dan is hy weg. Dan's die deure nie eers gesluit nie, of as ek die deur sluit dan breek hy die deur oop. Dan doen hy daai.*

Divan: *So hy het al in die verlede die deur afgebreek?*

Olivia: *Ja en hy't al die venster ook al stukkend geslaan.*

Divan: *I'm just wondering now, if you leave him, and didn't do that for him, what would happen or what has happened?*

Olivia: *The he just lies around the whole day or if he comes, then he's gone. Then the doors aren't even locked, or if I lock the door then he breaks the door open. Then he*

does that.

Divan: *So he has broken down the door in the past?*

Olivia: *Yes and he has also knocked the window out.*

Zelda explained how her son engaged in multiple destructive behaviours – damaging her vehicle, and stealing from them; primarily, to feed his drug addiction:

Zelda: *Maar Mark se probleem is Mark kan saam met ons gelewe het nog altyd, Mark se probleem is net hy't ons afgebreek. Ek praat nou vir jou Divan, hy't die, Saffire se loom uit gehaal, toe moet sy pa die kar reg nie, hy't nou sy pa en dit is ook die rede, nou kon die loom van die Pajero is ook uitgehaal, so daai-*

Divan: *Wat is dit?*

Zelda: *Die Pajero, die van.*

Divan: *Ja, maar wat het hy uitgehaal?*

Zelda: *Die loom, die hele bedrading onder die kar*

Divan: *Ja, so hy haal die bedrading uit?*

Zelda: *En dan brand hulle, dan koppel hulle mos die binnekant uit.*

Divan: *Oh oh hy verkoop die koper wat binne in is op die…?*

Zelda: *En ontdek die computer box wat die Pajero, wat uitgehaal, wat eintlik die ding laat ry en al…so daai ding, die enjins het oorgedoen gewees, alles is tot nuut. Nou dit is ook pap, jy kan nie, terugkry wat jy verloor het nie, waar gaan ek nou daai Pajero kan regmaak? Hulle is 'n computer vol, hoeveel gaan hulle vir my vra om die loom set in te sit? Is 'n enjin wat nou nuut van kop tot tone oorgedoen is. Tot nuut, jy kom, nie gaan nie kry wat jy verloor het nie. Baie verloor.*

Zelda: *But Mark's problem is he was able to live with us always, but his problem is just that he broke us down. I'm talking for you now Divan, he removed the Saffire's "loom", then his dad had to fix the car, he […] his dad and that is also the reason, now the Pajero's "loom" was also removed.*

Divan: *What is that?*

Zelda: *The Pajero, the van*

Divan: *Yes, but what did he remove?*

Zelda: *The "loom", the whole wiring under the car*

Divan: *Yes, so he removes the wiring?*

Zelda: *Then he burns it, then they connect the inside out*

Divan: *Oh oh he sells the copper that is inside on the…?*

Zelda: *And discovers the computer box that the Pajero, that's removed, that actually makes the car drive and everything, so that thing, the engines were redone, everything was destroyed. Now that is also flat, you can't, get back what you've lost, where am I going to fix that Pajero now? They are a computer full, how much are they going to ask to me install the "loom" set? It's an engine that was redone from top to bottom. Destroyed, you come, not going to get back what you've lost. Lost a lot.*

Sub-theme 2.3: Distressing experiences caused by having the illness. Caregivers also reported that they had to witness the patient in times of distress. This sub-theme only includes moments of distress that result from having schizophrenia – for example; patients reacting with a sense of fear to their auditory hallucinations.

Seven caregivers narrated about having to witness the patient enduring distress in the caregiving environment. Distressing moments were mostly marked by crying, fear, the patient feeling helpless; anxious; and depressed. Some examples of these experiences are presented below:

Olivia emotionally told me how her emotional state synchronised with Alfred's during distressing times. She explained that Alfred cried because of the realisation that something is wrong with him and the pain that accompanied his experience. She stated:

Olivia: *Hy't vir laas week twee dae so aaneen gehuil, sy suster vra wat makeer, hy sê: 'My brein', die pa vra wat makeer, 'Hier's iets verkeerd in my brein. My brein is seer en almal…' ek meen nou moet ek vir hom… hmm?*

Divan: *En om jou kind so te sien deur-*

Olivia: *Ja, ja en-*

Divan: *Deur dit te gaan*

Olivia: *Ja [bevestigend] en hy huil nie sag'ie, hy huil kliphard. Kliphard huil hy en ek meen hoe moet ek voel, hmm? Ek meen ek kan mos nie net laat hy daar lê en huil'ie, ek moet na hom toe gaan ek moet vir hom mooi vra 'Alfred wat makeer?' Dan sê ek ook vir hom 'Maar Alfred, daar waar jy gaan issie goed'ie. Die mense wat jy by gaan gaan dit issie goed'ie…' En ek sê 'Jy kom hier en dan onstel jy weer vir my en jou pa' Ek sê 'Ons issie meer jonger nie, ons raak ouer, huh?'*

Divan: *Maar hoe voel jy as ouer daai tyd wat jy so met Alfred… moet gesels en wanneer hy huil?*

Olivia: *Dan, ek voel dit saam. Ek voel dit saam.*

Olivia: *Last week he cried like that for two days non-stop, his sister asks what's wrong, he says: "My brain", the dad asks what's wrong, "There's something wrong in my brain. My brain hurts and everyone…" I mean now I must […] for him… hmmm?*

Divan: *And to see your child going through-*

Olivia: *Yes, yes, and-*

Divan: *To go through that.*

Olivia: *Yes [confirming] and he doesn't cry softly, he cries out loud. Out loud he cries and I mean how must I feel, hmm? I mean I can't just let him lie there crying, I must go to him and ask him nicely, "Alfred, what's wrong?" Then I also tell him, Alfred, there were you go isn't good. The people that you go to, that isn't good…" And then I say "You come here and you upset me and your dad again" I say, "We aren't younger anymore, we're getting older, huh?"*

Divan: *But how do you feel as parent during that time with him… where you have to talk to him and when he cries?*

Olivia: *Then, I feel it with him. I feel it with him.*

Betty talked about the fear of having schizophrenia introduced to her son's life: *"Hy was bang. Ek weet nie hoekom was hy bang. Sy siekte het hom bang gemaak" ("He was scared. I don't know why he was scared. His illness made him scared").* She later discussed the same topic: *"Hy wil- hy's amper soos- hy was maar net- hy was net bang. Hy moet- hy was bang, bang, bang. Ek weet nie hoekom was hy bang vir die siekte nie". ("He wants to- he's almost like- he was just- he was just scared. He must- he was scared, scared scared. I don't know why he was afraid of the illness").*

Lastly, Zuby informed me about the emotional turmoil that a person with schizophrenia experience:

They go into the moods, the swing moods, getting angry and getting anxious and becoming depressed, you know, and becoming introvert all the time, and scared and things like that, and hearing voices… Because that's what Peter used to do, he used to hear voices when he's sleeping, and he used to talk to himself.

Sub-theme 2.4: Patient abused by community members. By having the person with schizophrenia living at home, caregivers, at times, had to witness their loved ones being abused by others in the community. Sometimes, this abuse was subltle – when patients were

exploited or manipulated to act in others' favour. However, this sub-theme also encompasses caregivers' accounts that indicated on physical, emotional, verbal and non-verbal abuse from members in the community.

Zelda felt that her son submitted to peer pressure, as he wanted to gain popularity from others, possibly drug users, in the community. As a result Mark was exploited by others when they asked him to steal from Zelda's home:

Zelda: *Hulle word gou gebruik ook, hulle word gebruik deur ander mense.*
Divan: *Vertel my, ek stel baie belang.*
Zelda*: Daai kinders hulle's mos nou klomp daar en dis miskien almal is druggies, kyk hier man, kyk hier, dit gaat haal dit, het jy nie dit nie. Oh as Mark net, maar is dit hoekom Mark kom steel ook om te verkoop laat hulle kan… hy wil nou in wees in die outjies en hulle's saam.*

Zelda: *They get used quickly too, they get used by other people.*
Divan: *Tell me, I'm very interested.*
Zelda: *Those children they're a bunch there and it's maybe that they're all druggies, look here man, look here, it goes and fetches it, if you don't have it. Oh if Mark only, but that is why Mark also comes and steals to buy so that they can… he wants to be 'in' with the boys and they're together.*

Maryna stated that her son was physically abused and robbed at work:

Maryna: *Baie dinge, hulle 'het dan vir hom geslaan daar… [stilte]*
Divan: *Vir Martin nou? [om uit te klaar]*
Maryna: *Ja [bevestigend]… en en hulle't vir hom sy geld afgevat…[pouse] hulle't baie dinge aan hom gedoen, hulle't hom baie seergemaak as hy so skofte gewerk het…*

Maryna: *Many things, they hit him there… [silence]*
Divan: *Martin now? [to clarify]*
Maryna: *Yes [confirming]… and and they took took his money from him…[pause] they did many things to him, they hurt him a lot when he was working shifts…*

Theme 3: The effect on the caregiver's social environment. This was the third theme that emerged that describes aspects of caregiver burden. Having the patient live at home also had an effect on the social environment of the caregiver. This implies that the

people with schizophrenia influenced caregivers' interactions and relationships with others – family and friends. Patients' behaviour affected social relationships.

The patients affected caregivers' social lives mainly in three ways. First, having patients live at home induced strain on caregivers' relationships with other family members. Second, the patient was in conflict with the caregiver and significant others at home. Lastly, on the extreme end of the spectrum, caregivers withdrew from social interaction, and isolated themselves after becoming a carer.

Sheila stated that having children with schizophrenia put additional strain on her marriage with Skollie: *"Well, it took a lot of strain on our marriage, first of all, not that we don't have problems… Because now we had two, two of them you see?"*

Moreover, the patient also induced conflict between family members at home. Zelda explained how she had quarrelled with her husband, as her and her husband disagreed on how to handle their son:

> Divan: *Dit klink of daar 'n stryery was op 'n stadium?*
> Zelda: *Ja daar is stryery want, is ek wat ek piep piep hom op. Is groot, is mansmense hulle moet vir hulle life fight laat hulle self kan fight daar buite, jy moet op, jy moet kinders op piep wat nie daaroor gaan nie. Ek, by my het dit gegaan oor, ek sien daar's fout en as hulle dit vroeg kan keer dan wil ek dit so hê.*
>
> Divan: *It sounds like there was an argument at a stage?*
> Zelda: *Yes there are arguments because, it's me I spoon feed him. They're big, they're men they must fight for their life so that they can fight for themselves out there, you must, you must spoon feed children who don't go about that. Me, for me it was about, I can see there's something wrong and if they can prevent it early on then I want it that way.*

Six caregivers also voiced stories indicating conflict between the patient and others. Charlie said: *"Hulle twee [pouse] hoe kan ek sê, kom net, het nooit goed oor die weggekom nie. Hulle't nooit goed oor die weggekom nie" ("Those two [pause] how can I say, just get, have never got on well. They never got on well")*. Natalie described a similar experience when she referred to an argument between Brett and her twin daughters:

> *Miskien oor 'n simpel ding. Hy sê miskien nou, okay die twins is Taybah en Tahiba né daai's hulle name, nou sê hy miskien vir hulle, kyk gou of die, of daar 'n ding in die laai is. Nou kyk hulle, daar is nie 'n ding nie, dan sê hulle vir hom dit is nie daar nie,*

hy verstaan nie, 'Kyk reg man of dit daar in die laai in is'. Nou kom daar 'n argument [pouse] in the house…

Maybe over a silly thing. He maybe says, okay the twins are Taybah and Tahiba, those are their names, now he maybe says to them, quickly see if the, if there's something in the drawer. Now they go and look, there's nothing, then they tell him it's not there, he doesn't understand, "Look properly man see if it's in the drawer". Now an argument starts [pause] in the house…

Lastly, two caregivers appeared to be socially isolated, with minimal social engagement. Charlie explained that, at times, he does not speak to his son when they are at home. This creates a sense of isolation within Charlie, which on its turn leaves him feeling discouraged. He stated in our interaction:

Divan: *So die stimulasie is vir jou belangrik?*

Charlie: *Ja, ek hou van lekker gesels, ons kan praat [verwys na Conrad]… maar as ek by die huis is praat ek nie. Ek is, ek is soos, dan's ek geisoleerd… Uh [dink] hoe kan ek sê? [pouse] ek raak [pouse] ek raak mismoedig… ek lê daarso, ek mis my vrou.*

Divan: *So the stimulation is important for you?*

Charlie: *Yes, I like talking, we can chat [referring to Conrad]… but when I'm at home I don't talk. I am, I am like, then I'm isolated… Uh [thinking] how can I say? [pause] I become [pause] hopeless… I'm lying there, I miss my wife.*

Cassey, again, stated that she had few friends and that her family forms the boundaries of her social interaction: *"Ek het nie eintlik vriende nie, ek het net familie, my susters" ("I don't actually have friends, I only have family, my sisters").*

Theme 4: Emotional impact on caregiver. When becoming a caregiver, and by having the patients live at home after diagnosis, affected the emotional state of caregivers in my study. Therefore, this theme encompasses narratives about the impact that caregiving had on carers. Moreover, the theme can be divided into two sub-themes that more specifically illustrate the effects that being a caregiver has on the carer.

Sub-theme 4.1: During diagnosis. This sub-theme specifically focuses on caregivers' emotional reactions to the first time they heard about the patient's diagnosis from a mental healthcare provider. Prior to this moment caregivers may have suspected that their loved one was displaying symptoms of schizophrenia; however, an official diagnosis was not yet made

by a mental healthcare professional.

During diagnosis, it is possible for caregivers to experience a wide range of emotions, as Skollie mentioned: *"Dis moeilik vir my. Moeilik kan dit nie eintlik beskryf nie, baie verskillende emosies wat opdek in ŉ mens, baie verskillende emosies" ("It's difficult for me. Difficult doesn't really describe it, many different emotions that crop up in a person, many different emotions")*. However, caregivers mainly experienced three different emotions at the stage of diagnosis – disappointment, heartache, and shock.

Both, Cassey and Zelda reported that they experienced disappointment when their children were diagnosed. They attributed this disappointment to the fact that they had hopes and ideals for their children, and at that stage these were diminished by the diagnosis. Cassey stated: *"Ek was erg trots gewees, en ek het- en ek ideale vir my kinders gehad [sy huil]. Daarom was dit vir my 'n teleurstelling gewees, maar ek wil altyd daar wees maar vir hulle" ("I was very proud, and I had- and I had ideals for my children [she cries]. That's why it was a disappointment for me, but I always want to be there but for them")*. Zelda confirmed Cassey's experience: *"Oooh ek was baie teleurgesteld…ek het vooruit… ek het vooruitsigte gehad vir hulle" ("Oooh I was very disappointed… I had amb- I had ambitions for them")*.

Furthermore, Olivia cried while sharing her sense of heartache during the interview. Olivia stated: *"Ek het bad gevoel, ek as ek hier kom, als vir my droeë oë nie [huil], soos ek hier is, is ek altyd… waar ek gaan met hom. Is hartseer. Dis hartseer…" (I felt bad, I when I get here, everything for my dry eyes [cries], as I am here, I am always… where I go with him. It's sad. It's sad")*. Sheila also experienced heartache, as Shirley was diagnosed with schizophrenia after her son who also lives with the disorder: *"Oh I cried [softly]… I cried like a baby! Because I thought, jirre I've got two of them!"*

Lastly, five caregivers experienced a sense of shock upon diagnosis of the patient. Suzette's experience was evoked, as she thought that Fred would no longer be able to live a "normal" life: *"dit was vir my 'n groot skok want ek het gedink hy sal miskien nooit weer 'n normale- 'n normaal kans en so" ("it was a big shock for me because I thought he would maybe never have a normal- a normal chance again and so on")*.

Sub-theme 4.2: Continuous caregiving over a long period. Having to care for a person with schizophrenia may be long-term orientated or for some a lifelong responsibility – as illustrated in Table 1 earlier in this chapter. As a result, caregivers experience a range of emotions throughout the caregiving process. Thus, this sub-theme specifically focuses on caregivers' emotional reactions throughout the caregiving experience.

After data analysis, 13 different emotions emerged that described caregivers'

emotional reactions throughout the caregiving task. The emotions included:

1) feeling ashamed,
2) disappointed;
3) a sense that life had become "swaar" (difficult);
4) fear;
5) frustration;
6) guilt;
7) heartache;
8) a sense of helplessness;
9) experiences of loss;
10) feeling stigmatised;
11) feelings of distress;
12) uncertainty; and
13) worry.

It should be noted that the 13 presented emotions were regarded as accurate descriptions of caregivers' experiences in my study. However, for practical reasons, it is not possible to provide caregiver accounts for every emotional experience. Therefore, I only provide examples of the five emotional experiences that loaded the highest in Atlas.ti.

First, I provide narratives where caregivers experienced a sense that life had become difficult. Six caregivers provided narratives of this experience in their interviews. Olivia very emotionally shared how difficult her life had become. In her case, it appeared that a number of life stressors – a decline in personal health, Alfred's problematic behaviour, and a lack of social support from family – had taken its toll on her. These stressors accumulated, and the result was this sense that life had become difficult for her. She stated:

> *Kyk soos ek ook, ek het arthritis, die arthritis laat my partykeer so laat lê, ek kan nie goeters optel nie, ek kan nie werk nie, dan is daar partykeers… ek wil 'n ding 'n ding doen maar dan kan ek dit nie doen nie [begin huil]… want ek kan dit nie doen nie want…want ek is so kwaad vir die kind, hy luister nie en antwoord nie. Ek meen ek gaat vir help, maar dit vat so lank wat ek moet kom vir help en so aan [baie emosioneel]. Daar's tye as ek my opwerk dan raak ek net so drowsy, en as ek my kry dan's ek uit, dan sorry, dan loop die, dinge so uit hier by my, dan's ek uit vir 'n kwartuur, dan weet ek nie wat om my aangaan…[huil] Dis swaar is, is baie swaar. Familie sal nie weet wat ek deurgaan nie. Hulle kan net lekker praat, maar hulle help*

nie. Hulle help nie.

Look as I also, I have arthritis, the arthritis sometimes makes me lie in so late, I can't pick things up, I can't work, then there are sometimes… I want to do a thing to do a thing but then I can't do it [starts crying]… because I can't do it because… because I am so angry at the child, he doesn't listen and he doesn't answer. I mean go for help, but it takes so long that I have to come for help and so on [very emotional]. There are times when I get worked up then I just become so drowsy, and when I see again then I'm out, then sorry, then the stuff runs, runs out of me here, then I'm out for fifteen minutes, then I don't know what's going on around me…[cries]. It's tough, it's very tough. Family won't know what I go through. They can just talk nicely, but they don't help. They don't help.

Skollie experienced a similar emotion, but voiced it differently:

Skollie: *Dis ŉ damn onplesierige... Vir ŉ ouer dis ŉ hartsterkende ondervinding. Dis ŉ vloek, daardie illness. Ek wil nie my eie vyand hê hy moet die mental illness hê nie.*
Divan: *Mm hm. Jou hele lewe word om ver gegooi.*
Skollie: *I wouldn't wish it on my own bloody dog, this mental illness.*

Skollie: *It's a damn unpleasant… for a parent it's a heart-wrenching experience. It's a curse, that illness. I don't want my own enemy to have the mental illness.*
Divan: *Mm hm. Your whole life becomes thrown off course.*
Skollie: *I wouldn't wish it on my own bloody dog, this mental illness.*

Second, caregivers also experienced a sense of frustration while being a carer. Zuby stated that she felt frustrated because she could not control Peter's behaviours:

But it was frustrating for me also, it was very frustrating because I couldn't control it, you understand, from my point of view, from being a mother, I couldn't control him, "Oh, you must go bath," and that, and I didn't use violence or anything like that on him, you know, which is wrong. Some- some people would do that because they're not responding, you know, act violently and things like that, but I just left him.

The third emotion that was prominent in caregivers' narratives was the sense of guilt that caregivers experienced after the patient became ill. Most caregivers felt that it was their fault that their children became ill and blamed themselves for this. Doris expressed her guilt

when she told me that she wondered if she had sinned and therefore gave birth to children with schizophrenia: *"My ander kinders het dit ook [pouse] ek het vir my man gevra wat het ons gesondig?" ("My other children also have it [pause] I asked my husband what have we sinned?").* Sheila also experienced a similar experience to that of Doris:

> Sheila: *Well, everyday was a challenge because you don't know from the time she wakes 'till the time you know she's settled in to, you don't know because there was things that she perhaps said, or did, or say to me that you know, that I as a mother felt…[pause] even today sometimes I still feel that way… where I just produced children that's … [pause] something wrong with them, I wasn't the good wife, my punishment… you know you would beat yourself up that way!*
>
> Divan: *You felt that you were responsible for this?*
>
> Sheila: *Yes 'cause you you felt… the man, his only son, he's a schizophrenia now too. And now the youngest also, so you know you always beat yourself up about that [pause] this is [pause] I'm not a good person I am [pause] you know I don't know how to read but you just feel that way. Because things go wrong in a marriage, you get thrown perhaps it means a argument – who is responsible? [asked with urgency] You know all that kind of the things come into play…*

Fourth, many caregivers experienced loss, as an emotion, throughout the caregiving process. Loss was mostly attributed to two factors. First, caregivers felt that they had lost the person they knew before the patient became ill. Second, caregivers had ideals and hope for the patient, and these were lost after the patient became ill.

Natalie expressed her and her family's sense of loss of the person they knew before Brett had schizophrenia:

> *Die Saterdag toe hy siek geraak het die eerste keer, het hy vloek vloek in die huis ingekom. Vloek vloek en daai's nie die Brett wat ons ken nie, né? Het hy vloek vloek in die huis ingekom en toe ons vir hom vra wat is dan nou fout met hom, laat hy nou so uitvaar, hy't my een- ek en my ma en my een vriendin was daar, en toe begin sy even te huil, because ons ken mos nou nie vir hom sò nie.*
>
> *That Saturday when he got ill the first time, he came into the house swearing. Swearing and that's not the Brett we know, hey? He came into the house swearing and when we asked him what was wrong with him, that he was acting out like that, my one friend he- me and my mom and my one friend were there, and then she even*

started crying, because we don't know him like that.

Doris explained how her daughter's behaviour regressed after diagnosis, and in the process losing the old Dawn:

Hoe wil mens sê, met Dawn [pouse] dan's Dawn's soos 'n babatjie mos, so sy was iemand- nie meer, hulle's nou nie meer soos iemand wat nou groot is en volwasse nie, dan is hulle soos klein kindertjies wat jy alles moet doen vir hulle. Dan moet jy weer vir hulle voer, jy moet nou vir hulle dink, ek moes vir haar self vir haar gedink het wat sy moet doen.

How does one want to say, with Dawn [pause] then Dawn's like a baby, so she was someone- not anymore- they're not like someone anymore whose grown up and mature, then they're like small children who you have to do everything for them. Then you have to feed them again, you must think for them now, I had to think for her what she had to do.

Charlie experienced a sense of loss, he had lost the dreams and hopes he had for Conrad:

Charlie: *Ek het altyd gesê hy's eendag 'n WP speler of so, maar hy't nooit gevorder op, verder gevorder op skool nie, daarna het standerd 6 standerd 7 het hy nooit meer beginne rugby speel nie en [pouse] en atletiek aan deelgeneem nie en dit. Waar ek weer reg deur my skooljare [pouse] geboks het en rugby gespeel het sulke goed…*
Divan: *So daai hoop en aspirasies wat jy vir Conrad gehad het, met die siekte en oor ander redes het ook nie gebeur nie?*
Charlie: *Ja my vrou't ook maar altyd gesê, hoekom is hy anders gewees?*
Divan: *En nou, hy was fisies, kan ek, hy's fisies steeds 'n sterk seun en maar hy was aktief en fiks*
Charlie: *Fiks gewees*
Divan: *Hoe laat dit jou voel dat hy nie meer daai dinge so kan doen nie?*
Charlie: *Ja 'n [pouse] 'n bietjie teleurstelling want ek't altyd gedog, een van die kinders gaan eendag my goed, voorvolg.*

Charlie: *I always said one day he'll be a WP player or so, but he never progressed, progressed very far in school. Thereafter standard six, standard seven, he never started playing rugby again and [pause] and taking part in athletics and that. Where I*

again throughout my school years [pause] did boxing and played rugby and stuff like that…

Divan: *So those hopes and aspirations that you had for Conrad, with the illness and for other reasons, also didn't happen?*

Charlie: *Yes, my wife also used to say, why was he different?*

Divan: *And now, he was physically, I can, he's physically still a strong guy and but he was active and fit*

Charlie: *Was fit*

Divan: *How does it make you feel that he isn't able to do those things anymore?*

Charlie: *Yes a [pause] a bit disappointing because I always thought, one of the children will one day carry forth my stuff.*

Fifth, seven caregivers reported sensing stigma as caregiver. The content of the stigma was more directed towards the patient; however, it did not escape caregivers' perception. It was also interesting to hear that, at times, the caregiver's family stigmatised the patient. Charlie provided evidence for the latter:

Ek wil hom al gevat en gesê kom ons gaan Johannesburg toe, net vir 'n week na vriende en familie toe. Maar ek, ek voel ek kan hom nie saamvat nie… Hy gaan nie met hulle praat nie hulle gaan, eerste wat hulle vir my gaan vra is, is daar iets fout met hom?

I've wanted to take him and say let's go to Johannesburg, just for a week to friends and family. But I, I feel I can't take him with… he's not going to talk to them he will, first thing they're going to ask me is, is there something wrong with him?

Similarly, Doris also perceived stigma from a community member:

En toe die aand toe kom Noel daaraan toe sê Noel vir ons, hy wil die brood breek, en toe ons nou praat nou van die, toe vra hy nou wat, wat het, hoekom? Wat makeer Dawn? Toe sê ek vir hom, hulle sê Dawn het schizophrenia! Toe sê hy my, 'Oh bull, it's not schizophrenia! It's bull, it's witchcraft'…hy't my net so gesê.

And then that night Noel arrived and and Noel told us, he wants to break the bread, and when we were talking about the, then he asked what, what did, why? What's wrong with Dawn? Then I told him, they say Dawn has schizophrenia! Then he told me, "Oh bull, it's not schizophrenia! It's bull, it's witch craft"… he told me just like

that.

Lastly, Maryna voiced reports of stigma as well:

> *Nou Martin is een wat jy kan nou moeilikheid met my maak maar more gaat ek jou weer kry… [pouse] maar nou, maar dan gaat ek jou op 'n ander manier kry… [pouse] toe het die vroumens glo daarso uitgevaar, 'ja jou kinders is almal befok! [maak vrou na]' en ek weet nie wat alles nie. But I just-*
>
> *Now Martin is one who you can make trouble with me today but tomorrow I'm going to get you again… [pause] but now, but then I'm going to get you in another way… [pause] then apparently the woman acted out there, "yes your children are all fucked!" [imitating woman] and I don't know what else. But I just-*

Theme 5: Patient dependency. This was the fifth theme that emerged in the domain of caregiver burden. Caregivers experienced patients as individuals who become dependent on others, and specifically the caregiver, after being diagnosed with schizophrenia. Thus, this theme encompasses experiences where caregivers justified patients as dependent.

Six participants reported experiences of patient dependency in their interviews. Interestingly an example of patient dependency occurred while I was interviewing Skollie. During our interview the patient interrupted us and asked for Skollie to hurry up and conclude the interview, as she needed him to take her home. Once at home, Shirley further depended on another to take her to an appointment. Skollie stated before Shirley's interruption:

> *Maar hier kry jy nie ruskansie nie want die een, hulle bel, die kind is siek en die ander een wil hiertoe gaan en die ander een wil daai. Toe dink ek, man, Shirley, ek het nou daai kar gekoop- get your bladdy arse to work man. Ons is oud, ons kan nie meer sien nie, man.*
>
> *But here you don't get a chance to rest because the one, they phone, the child is sick and the other one wants to go here and the other one wants this. Then I thought, man, Shirley, I bought that car now- get your bloody arse to work man. We are old, we can't see anymore, man.*

[Shirley interrupted]; Skollie continued: *"Sy is nou weer haastig sy's ge- You see, dit is wat ek sê, sy is baie- as dit twelve minutes past eleven haar- sy's nou moeg van hier sit, haar*

transport kom, ek weet ook nie" ("She is hasty she's – You see, that is what I'm saying, she is very- if it's twelve minutes past eleven her- she's now tired of sitting here, her transport is coming, I also don't know").

Charlie further reported how Conrad depended on him:

> Charlie: *Sover depend hy op my…En op sy ouderdom moes hy al lankal gewerk het en hy moes… hy gaan hy't werke gehad wat, hy kan dit nie hou nie, sy konsentrasie daar nie…*
>
> Divan: *En jy kom agter hy depend op jou?*
>
> Charlie: *Ja, nee hy depend op my, elke dingetjie…elke dingetjie.*

> Charlie: *So far he depends on me… and at his age he should've been working long ago and he should've… he goes he had jobs that, he can't keep them, his concentration not there…*
>
> Divan: *And you realise he depends on you?*
>
> Charlie: *Yes, no he depends on me, every single thing… every single thing.*

Theme 6: Living with a sense of obligation to care. Caregivers also felt obligated to care for the person with schizophrenia. This experience was predominantly marked by the idea of "moet sorg" (must care), as caregivers felt responsible to commit to this role.

Eleven caregivers expressed a sense of obligation to provide care for the patient. Zelda stated that she must provide care to Mark, and that it is her choice to do so: *"Ek moet maar… die dag as ek daar, jy gaan nie vir my sê doen dit nie. Ek is my eie person" ("I have to… the day that I, you aren't going to tell me what to do. I am my own person").* Natalie provided a similar account: *"verder aan moes ek maar vir hom gesorg het" ("further on I had to take care of him").* Lastly, Betty also felt that God has given her this responsibility, and as a result, she experienced a sense of obligation to care: *"God het ń ding in onse pad gesit, en as hy ń ding in ons pad gesit het dan moet ons dit kan doen" ("God put something on our paths, and if he puts something on our path then we must be able to do it").*

Theme 7: New activities for caregiver. Being a caregiver introduced new activities for the carer. Therefore, this theme represents narratives that indicated new behaviours that the caregiver engaged in with the uptake of this role.

Caregivers in my study reported a number of additional activities that were exercised in caring for a person with schizophrenia. These acts included: preparing food, cleaning the

patient's living space, doing extra shopping to provide for the patient as well; doing the patient's washing, acting to maintain the patient's hygiene. However, there were four activities that were commonly reported by caregivers: 1) accompanying the patient to hospital visits, 2) supervising the patient's medication use, 3) listening to the patient, and 4) "dophou" (keeping an eye on the patient). Examples of each are provided.

Seven caregivers reported that they had to accompany the patient to hospital appointments. Betty told how she accompanied her son to doctor appointments: *"Toe het ons met hom mos elke dag doktor gekom" ("Then we came to the doctor with him everyday").* Maryna similarly stated how she accompanied her son to numerous hospital visits for diagnostic evaluations and treatments:

> *En ons het nou van die een dokter na die ander dokter van die een dokter na die ander dokter gegaan… en ons was 'n stadium gewees by so baie hospitale en so baie dokters [pouse] en hulle't gevat, hoe sê hulle? Scans neh? Brain scans…[pouse] alles van hom gevat in die… en toe't hulle vir ons by Red Cross kry, toe't hulle vir hom gesit op 'n sekere pil.*
>
> *And we went from the one doctor to the other doctor from the one doctor to the other doctor… and we were at one stage at so many hospitals and so many doctors [pause] and they took, how do they say? Scans neh? Brain scans… [pause] took everything of him in the … and then they got us to Red Cross, then they put him on a certain pill.*

Once the patient was put on antipsychotic medication, caregivers commonly had to supervise patients' medication use. Four caregivers provided acounts for this new responsibility that accompanied the caregiving role. Doris explained how she supervised Dawn's medication use: *"Maar dan's ek huis toe gekom het, dan't ek na, dan moet ek haar nou omsien dat sy haar tablette en medikasie inkry…" ("But then when I came home, then I went to, then I have to take see to her that she takes her tablets and medicine").* Charlie also stated that he reminded his son, and thereafter, supervised Conrad's medication use: *"ek moet eintlik kyk, elke oggend, elke aand… Dis jou pille nou, en dis die tyd" ("I must actually look, every morning, every evening… that's your pills now, and that's the time").*

Six caregivers reported that they had to listen to the patient, at times when the person with schizophrenia needed this. Zuby reflected how she to act by listening to Peter when he needed a listener:

> *You know, pay attention to them, they have their ups and downs also, and when they*

want- they come out of their own to talk to you then you must listen to them, what they have to say, because it's not always that they come out and have a conversation with you.

Lastly, a common new activity for caregivers was to keep an eye on the patient at home. Cassey mentioned that she frequently keeps an eye on her son: *"Ek- ek- ek hou vir Chris baie dop. Ek hou vir Chris baie dop, ek praat gedurig met hom saam, ek en hy het staan gesels baie" ("I- I- I keep an eye on Chris often. I often keep an eye on Chris, I talk to him frequently, him and I stand and chat a lot")*. Doris told how she had to keep an eye on Dawn on a weekend away from home: *"Toe moet ek daai hele, ons het 'n lang naweek gehad, na haar dopgehou het…" ("Then that whole, we had a long weekend, I had to keep an eye on her…").* Similarly, Betty kept a watchful eye on Brett during moments when he was scared:

Ons moet hom elke dag dopgehou het. Elke oomblik moet ons dit doen want hy was bang, hy wil nie uitgegaan het nie. Ek moes saam met hom toilet toe gegaan het, hy was bang om toilet toe te kom.

We had to keep an eye on him everyday. Every moment we had to do that because he was scared, he didn't want to go out. I had to go to the toilet with him, he was scared to come to the toilet.

Theme 8: Physical strain on caregiver. Caregivers experienced physical strain after taking on this role. On the one end of the spectrum, this theme includes narratives that provide evidence of the physical burden that caregiving had on the caregiver. At the other end of the spectrum, this theme describes instances where caregivers were entirely physically drained – states of energy depletion.

Betty reported how difficulties that were caused by her son's schizophrenia affected her: *"Dit het my miskien- so sal ek sê, jy voel moeg en gedaan, veral as jy moet sukkel met dit, maar ek meen dit raak mos nou jou body language" ("That maybe made me, I'll say, you feel tired and knackered, especially if you have to struggle with that, but I mean that becomes your body language")*. Charlie explained how he and other had realised the physical toll having to care introduced:

Charlie: *Ja want kyk ek [pouse] bedoel, dit gaan my siek maak. Ek gaan siek raak daarvan… Almal sê vir my klaar, look how thin you are, jy teer uit. Daai vrou het dit*

> *ook gesê, hoe't sy't ook gesê teer uit, teer uit, because… Hierdie laaste paar maande het ek uitgeteer…*
> Divan: *Mmm, so jy't definitief-*
> Charlie: *Ek voel moëer, want ek doen meer. Ek doen baie meer as wat ek voorheen gedoen het…*

> Charlie: *Yes because look I [pause] mean, it's going to make me sick. I'm going to get sick of it… Everyone tells me already, look how thin you are, you are burning out. That woman also said it, how did she also say, burning out, burning out… These last few months I've been burning out…*
> Divan: *Mmm, so you definitely-*
> Charlie: *I feel more fatigued, because I do more. I do lots more than I did before…*

Additionally, Sheila reflected how caregiving put strain on her physically, emotionally, and mentally: *"It was a very tiring, emotionally, mentally… it took a great toll on my- on my health itself…"*.

Theme 9: Disruption. Various aspects of caregivers' lives were disrupted after the patient became ill. This can be attributed to two causes. First, being a caregiver demanded the carer to offer a part of their life to the patient. Second, patients, at times unexpectedly, required the caregiver's presence – thus disrupting the caregiver's current state of affairs. Therefore, this theme includes narratives that indicated how caregivers' lives were disrupted by having to care for a patient.

Being a caregiver disrupted carers' life in two main domains. First, carers' usual sleep pattern was disrupted. Second, caregivers' career and responsibilities related to it were disrupted, as the caregiver usually had to leave work to attend to the needs of the patient.

Doris reflected how she could not sleep at night when Dawn experienced hallucinations: *"ek was elke dag, mens slaap nie in die nag nie [pouse] want dan is sy vreesbevange [pouse] was sy vrees- sy sê dis die mense hulle jaag vir haar en dan sien sy en sy hoor stemme…" ("everyday I was, you don't sleep at night [pause] because then she is anxious [pause] she was fear- she says the people chase her and then she sees and she hears voices…")*. Olivia also stated that she could not sleep at night, as she feared that Alfred may harm them when he was under the influence of cannabis:

> *Ek meen kan mos nie elke keer slaappille vat ek meen ek moet ogie oor hom hou want daar's party aande as hy gaan rook het dan kom hy terug dan slaap hy nie. Ek moet*

eintlik die messe en die skep goeters moet ek wegsteek… want jy weet nie wat in sy mind aangaan nie.

I mean can't take sleeping pills every time I mean I must keep an eye on him because there are some nights when he's gone for a smoke then he gets back then he doesn't sleep. I actually have to hide the knives and the sharp things… because you don't know what's going on in his mind.

Moreover, four caregivers narrated accounts of how their careers and responsibilities were disrupted after the patient became ill. Betty explained how her son had become her first priority and that she chose to quit her job to provide care to him:

My lewe het- verstaan dat ek het ek het 39 jaar gewerk, hoor, en my prioriteit het my kind gewees want hy nou- so ek het afgedank van my werk, en ek het hom altyd gebring, ek was altyd saam met hom, period.

My life- understand that I worked for 39 years, listen, and my priority was my child because now he- so I resigned from my work, and I always brought him, I was always with him, period.

Zelda told about the day when Mark escaped from Stikland hospital and how she had to leave her work to search for him on the street:

Hy is verlede keer, toe's hy ontsnap, en toe bel hulle vir my by die werk, by hom, my man, toe moet ons, kom ek my man moet uit Durbanville uit kom, vir my kom uit die Kaap want ek gaat nie nou trein vat nie en kom ons kom, toe't hulle gebel hier vandaan ons mòèt vir hom kry.

Last time he was, then he escaped, and then they called me at work, with him, my husband, then we had to, come my husband and I from Durbanville, for me coming from Cape Town because I'm not going to take the train now and come we are coming, then they called from here, we must find him.

Theme 10: Difficulties experienced at healthcare services. Lastly, caregivers frequently experienced difficulties from professional healthcare institution staff. This theme includes narratives that illustrate these difficulties.

Caregivers predominantly experienced difficulties in four domains. First, caregivers

felt that, at times, healthcare providers were uninvested in their concerns and cases. Second, caregivers stated that they had not received adequate information about schizophrenia from physical healthcare providers. Third, it was interesting to hear that schizophrenia is frequently misdiagnosed by doctors. Fourth, caregivers found it difficult to access specialised mental healthcare resources. Examples of each of these four factors are provided.

Skollie explained how one doctor was listening to the radio during Skollie and Sheila's appointment with him:

> *En toe vat ons mos nou Brendan [Skollie en Sheila se ander seun met skisofrenie] na die Distriks Geneesheer en glo op, die brief van die Landdros by Parow, die Landdros Hof, sal hy alleenlik vir jou sien, want is my vrou lekker bedonderd in vir hom because hy sit en luister die rugby en die krieket en hy praat... Ja, mm hm.*
>
> *And then we took Brendan [Skollie and Sheila's other son with schizophrenia] to the District Healer and believe on, the letter from the Magistrate at Parow, the Magistrates Court, he alone will see you, because my wife is very upset with him because he sits and listens to the rugby and cricket and he talks… Yes, mm hm.*

Similarly, Doris mentioned how a doctor chose to go on lunch when Doris and Dawn approached him during an emergency:

> *Toe neem ons mos nou vir haar [pouse] uh dokter toe [pouse] na dokter X toe by Elsiesrivier, neem ons vir haar soontoe. Maar toe ons daar kom, toe wil hy nie vir my help nie. Toe sê hy vir my hy gaan nou op [pouse] uhm lunch, en middagete. Toe sê ek maar nee, u kan nie so sê nie, ek het u nou nodig, toe lê Dawn nou weer uit.*
>
> *Then we took her [pause] uh to the doctor [pause] to doctor X at Elsiesrivier, we took her there. But when we got there, then he didn't want to help me. Then he told me he's going on [pause] uhm lunch now, and lunch. Then I said but no, you can't say that, I need you now, then Dawn lay there unconscious again.*

Doris also provided evidence for the lack of information about schizophrenia and that clinicians provide insufficient information:

> Divan: *Wat het die dokters als vir jou vertel van die, van die skisofrenie?*
> Doris: *Hulle kan jou nie vertel nie! [pouse] huh-uh [nee]…dan hoeveel keer, dan hoekom? Waarom? [pouse] waavan, hoe kan 'n mens sê, wat is die afkoms daarvan? Dan sê Dr X het dan gesê, dit kan nie… dan sê ek ja ek het gelees al. Toe ek al die*

boeke uit gaan haal het, dan, nee Louis se boeke gelees het. Toe kan ek nou sien, hulle't nog nooit die oorsaak daarvan uitgevind nie… Oor van skiso- schizophrenia uitgevind nie… Hulle doen al die studies daaroor…

Divan: *So die dokters het nie altyd vir jou antwoorde op jou vrae…?*

Doris: *Nee, hulle't nie antwoorde vir my daarop nie. Hulle kan nie vir my sê nie!*

Divan: *What have the doctors told you about this, about this schizophrenia?*

Doris: *They can't tell you! [pause] huh-uh [no]… then how many times, then why? Why? [pause] from where, how can one say, where does it originate from? Then Dr X says, it can't… then I say yes I have read it before. When I went to fetch all the books, then, no read Louis's books. Then I could see, they've never discovered the cause of it… of schizo- schizophrenia haven't discovered it… they are doing all these studies about it…*

Divan: *So they doctors don't always have answers for you on your questions?*

Doris: *No, they don't have answers for me on it. They can't tell me!*

Five caregivers also reported that schizophrenia is commonly misdiagnosed by general doctors. Zelda stated that doctors had prescribed sleeping tablets to treat Mark's condition:

Divan: *'n GP kan jou nie help nie?*

Zelda: *Nee, ek sê daai mense kan nie vir jou help nie?*

Divan: *Kon 'n GP jou ook nie help nie?*

Zelda: *Nee, daai mense is, vat jou drie-honderd-en-vyftig rand, en gee 'n pil vir jou kind, maar die pille wat hulle gee is nie pille wat daai probleem help, skisofrenie nie. Hulle sal vir jou net miskien 'n slaappil gee, Retinol. Maar daai mense kan nie vir jou help nie. Toe sê ek maar daai dokter X gaan nie vir jou kan help nie, jy gaan nog dokters en, daai kind moet sielkundige toe gaan.*

Divan: *A GP can't help you?*

Zelda: *No, I say those people can't help you?*

Divan: *A GP also couldn't help you?*

Zelda: *No, those people are, take your three-hundred-and-fifty rand, and give you a pill for your child, but the pills they give aren't pills that help that problem, the schizophrenia. They'll maybe just give you a sleeping pill, Retinol. But those people can't help you. Then I said but that doctor X isn't going to be able to help you, you're*

going to more doctors and, that child needs to go to a psychologist.

Charlie also felt that general practitioners fail to properly assess and treat schizophrenia. He further stressed the importance of specialised mental healthcare service providers like psychiatrists. His message was communicated in our interaction:

Divan: *So die algemene praktisyn het, kan nie vir jou voldoen nie?*

Charlie: *Nee, nee hulle sal net vir hom die normale pille gee elke… dis al wat hy kry, net pille*

Divan: *En die psigiaters?*

Charlie: *Hierso het, Dr X ['n psigiater] het, jy kan sien die verskil gewees.*

Divan: *Is dit?*

Charlie: *Ja… toe hy hier weg is, na 'n tyd dan kan jy sien, my vrou't ook gesê dis heel anderste. Dis heel anderste dis asof hy, tyd is voor, asof hy excited is as hy kom weer terug hierso…*

Divan: *So the general practitioner, can't suffice for you?*

Charlie: *No, no they'll just give him the normal pills every… that's all that he gets, just pills.*

Divan: *And the psychiatrists?*

Charlie: *Here, Dr X [a psychiatrist], you could see the difference.*

Divan: *Really?*

Charlie: *Yes… when he left here, after a while you could see, my wife also said it's very different. It's very different it's asif he, time is ahead, he is excited when he comes back here again…*

Lastly, caregivers found it difficult to access specialised healthcare resources. Sheila reported the difficulty of accessing doctors at psychiatric hospitals such as Stikland Psychiatric Hospital:

Sheila: *So it was [pause] I tell I want to knock my head against this wall when I used to go there to the [pause] because they wanted to make absolutely sure that you're not just coming to dump him there.*

Divan: *Yaaa [Understanding] So for you as a parent and where you spoke about you knew something wasn't right-*

Sheila: Yes!

Divan: *But it sounds to me like you had to convince people that what you were experiencing-*

[Sheila interrupts]

Sheila: *Yes! [laughs] Even here at Stikland hospital, you know? They wouldn't let you see a doctor even [pause] you know? And you know this person is talking gibberish or whatever they – it's not right. But no, you first take that person to the day hospital. Now I knew those doctors there. They're not picking up, you say I'm normal? Because you can ask him anything, he will be normal. But I'm sitting with this problem [pause] so it was a very stressful, very very traumatic and stressful for me, as a mother [pause].*

Coping Strategies

This section describes the coping strategies that were reported by participants, as was conceptualised through the Transactional Model of Stress and Coping Theory that was introduced in Chapter Two. The themes and sub-themes derived during TA are summarised in Table 4.

Table 4

Themes and Related Sub-themes Related to Caregivers' Coping Strategies

Coping Strategies			
Theme family 1: Qualities of the caregiver			
Theme 1	Having a life partner		
Theme 2	Investing in their own needs		
Theme 3	Caregiver's religion		
Theme 4	Making sense of schizophrenia		
Theme 5	Fostering the positives		
Sub-themes (5.1-5.7)	Caregiver believes that he/she is doing the best of their ability when providing care	Caregiving with confidence	Noticing and hoping for recovery
	Love towards the person with schizophrenia	Reflecting with a sense of pride on the person with schizophrenia and having realistic expectations	Finding gratification in caregiving
	Caregiver personal growth		
Theme 6	Interactional tactics		
Sub-themes (6.1-6.2)	Not shouting at the patient	Not challenging lack of insight	
Theme 7	Being prepared		
Sub-themes (7.1-7.4)	Self-education on schizophrenia	Anticipating the patient's needs in advance	Living in the moment
	Being vigilant		
Theme 8	Cognitive-emotional processes		
Sub-themes (8.1-8.4)	Downplaying the	Avoidance	Acceptance

	impact of caregiving		
	"We got strength to carry on"		
Theme family 2: Utilising community resources			
Theme 9	Professional healthcare services		
Theme 10	Lay-care services		
Theme 11	Police services		
Theme 12	Financial support		
Theme 13	Social support		

As with the caregiver burden section, all themes in this section could fit into one of two theme families. I define and discuss each theme family in the next two paragraphs. Thereafter, the themes and sub-themes are discussed under their respective headings.

The first theme family – *qualities of the caregiver*, can be defined as properties of the carer that aided their coping. It mainly includes intrapersonal characteristics of and actions by caregivers directed into the caregiving environment or outside world. After analysis, eight themes emerged from the data set: *having a life partner*; *investing in their own needs*; *caregiver's religion*; *making sense of schizophrenia*; *fostering the positives*; *interactional tactics*; *being prepared*; and, *cognitive-emotional processes*.

The second theme family – *utilising community resources*, represents coping strategies that are commonly offered by others and services outside the immediate caregiving environment. Furthermore, it includes acts or services that are commonly accepted by caregivers to facilitate carers' overall quality of life. There are instances where caregivers may initiate interactions with community resources to aid their coping. Five themes emerged as members of the second theme family: *professional healthcare services*; *lay-care services*; *police services*; *financial support*; and, *social support*.

Theme 1: Having a life partner. Caregivers reported that having a life partner contributed to their coping. Therefore, this theme represents narratives where caregivers felt that their life partners facilitated their coping.

Five caregivers stated that their life partners helped them to cope with having the patient at home or with the caregiving responsibility. One example of this was provided by Doris when she reflected how her husband always supported her during distressing moments that Dawn experienced:

Ja …[bevestigend] My man kan byvoorbeeld, hy is maar 'n baie stil man is hy [pouse] 'n sagte man is hy want 'n mens moet met hom praat, dan huil hy sommer… dat, as hy nie eintlik 'n, hoe wil mens sê 'n hulp vir mens, nie eintlik nie. Want hy praat nooit ooit oor sy [pouse] dan raak hy sommer [pouse] dan moet ek maar my kindertjies maar so [pouse] met haar, as sy so bang is… maar hy't altyd my bygestaan.

Yes… [confirming] My husband can for example, he is a very quiet man he is [pause] a soft man he is because one must to talk to him, then he will just cry… that, if he doesn't actually, how does one want to say a help for you, not actually. Because he never talks about his [pause] then he becomes [pause] then my children I will have to like [pause] with her, when she is so scared… but he always stood by me.

Similarly, Cassey also stated with confidence that her husband stood by her: *"Ja, hy sal my bystaan, hy sal my bystaan in alles" ("Yes, he will stand by me, he will stand by me in everything")*.

Theme 2: Investing in their own needs. Caregivers also engaged in behaviours that addressed their own needs. Here, caregivers invested in themselves physically, psychologically, or socially in order to facilitate their overall well-being and coping.

Caregivers addressed, mainly, three needs. First, caregivers invested in their personal health. Second, caregivers engaged in recreational activities for enjoyment. Third, caregivers also realised the need for independence.

Charlie and Olivia both took responsibility for facilitating their health. Charlie discussed how he had decided to quit smoking cigarettes and drinking alcohol:

Ek is 'n ou wat glad nie rook nie, ek het dit nog nooit gesien nie…ek het gedrink jare terug [pouse] ek het vier en 'n half jaar laas gedrink…ek het net gesê dog ek dis 'n waste…dit het my begin siek maak [pouse] en toe dog ek nee, ek het net gesê, daai tyd dis nou klaar, nooit weer nie…

I am a guy that doesn't smoke at all, I have never seen it, I used to drink years back [pause] I last drank four and a half years ago… I just said I thought it was a waste… it started making my thoughts sick [pause] and then I thought no, I just said, that time is over now, never again…

Olivia stated that she had gone for help at the local hospital. She reported that she had been stressing for six year, and the doctor prescribe medication for intervention:

> Olivia: *Ja dit kom al ses jaar of so aan. Ses jaar kom dit al so aan, ja. Ek weet nie meer wat om te doen nie. Maar ek gaat maar vir help.*
>
> Divan: *Gaan jy vir hulp?*
>
> Olivia: *Ek is onder Kiewiets, oor die stressery en al die dinge ek is ook 'n Kiewiets pasiënt. Ek gaan ook nou Kiewiets toe.*
>
> Divan: *Okay en het Dokter Kiewiets al…met jou gesels en jou gehelp?*
>
> Olivia: *Hy't my net pille gegee om vir my calm en almal die dinge te maak but partykeers dan help die pille nie. Ek meen kan mos nie elke keer slaappille vat ek meen ek moet ogie oor hom hou want daar's party aande as hy gaan rook het dan kom hy terug dan slaap hy nie.*

> Olivia: *Yes it's coming along for six years or so. Six years it has been coming along, yes. I don't know what to do anymore. But I'm going for help.*
>
> Divan: *Do you go for help?*
>
> Olivia: *I am under Kiewiets, because of the stressing and all the things I am also a Kiewiets patient. I also go to Kiewiets now.*
>
> Divan: *Okay and has Doctor Kiewiets… spoken to you and helped you?*
>
> Olivia: *He just gave me pills toe make me calm and to do all the things but sometimes the pills don't work. I mean can't take sleeping pills every time I mean I must keep an eye on him because there are some nights when he has goes to smoke then he comes back and he doesn't sleep.*

She also added that she invests in her fitness; this rewards her with the ability to handle life responsibilities: *"Ek gaan… ek moet vir my ook fiks hou laat ek kan doen wat ek moet doen" ("I am going to… I have to keep myself fit as well so that I can do what I have to do").*

Theme 3: Caregiver's religion. This theme includes narratives where caregivers experienced their religion as a factor that contributes to their coping. The theme includes two aspects related to religion. First, caregivers engaged in religious behaviours such as praying, and attending church as coping mechanism. Second, however, to a lesser extent, caregivers were also open and accepted others' religious practises directed toward them or the patient – as this increased their coping.

Nine caregivers discussed religion as a coping agent. It was also interesting to note

that this was the theme that loaded with the highest number of quotes after analysis. Maryna stated that God's power was ever present in her life and that she would not have been able to face her experiences without God: *"Dan kan ek nie dink ek het dit alleen, ek meen God se krag was altyd by ons" ("Then I can't think that I did it alone, I mean God's strength was always with us")*. Skollie similarly stated that, if it had not been for God's grace, he would not have been able to cope with life events:

> *Ag, ek is bevrees met vrees. Het hy nie sy hand op ons gehou nie as sy kinders, dan weet ek nie. Dan weet ek nie. Ek wil ook nie daai paadjie loop nie. Dan was ons almal seker die kreefde gang af...*
>
> *Ag, I am afraid with fear. Had he not kept his hand on us as his children, then I don't know. Then I don't know. I also don't want to go down that path. Then we would all probably be down the […] path…*

Doris stated that if it had not been for God, she might have succeeded in committing suicide, as life stressors became too heavy to bear; God's "hand" prevented this:

> Divan: *Dit kon nie altyd maklik gewees het nie*
> Doris: *Dit was nooit maklik gewees nie! 'n Mens kan maar kyk, hier praat ek nou al die dinge, wat het ek alles al gedoen al? Amper my drie keer in die lewe, my lewe probeer om my lewe te neem… maar ek't nie geslaag nie…*
> Divan: *Sjoe!*
> Doris: *Deur mense … Deur die koggelry en dan nou [onduidelike audio] te maak. Maar toe ek my hand in die Here se hand sit [pouse] en so't ek daar deurgekom.*
>
> Divan: *It couldn't always have been easy.*
> Doris: *It was never easy! You can look, here I am saying all these things, what all have I already done? Almost three times in my life, my life tried to take my life… but I didn't succeed…*
> Divan: *Sjoe!*
> Doris: *Through people… through the teasing and then now [unclear audio] making. But when I placed my hand in the Lord's hand [pause] and that's how I got through it.*

Lastly, Maryna and Natalie both provided narratives on how others' religious practices reinforced their personal religious strategies. Their narratives may further also

suggest help-seeking behaviour (which is reported on in the *lay-care services* section of this chapter). They stated: *"En, toe't ek dit nou by die kerk aangegee vir die mense en hulle't toe nou gebid oor die saak en almal, soos jy mos nou weet, bid hulle toe nou saam gebed" ("And, then I gave it to the church to the people and then they prayed about the matter and everyone, as you know, prayed together prayer")* (Maryna); and *"So ons het [pouse] maar mense ingekry wat vir hom kan gebed ge- kan gebid het…Ons het different mense probeer net om 'n gebed mos nou daar te sit…" ("So we got [pause] people to come in who could prayer- pray for him… we tried different people just put a prayer there…")* (Natalie).

Theme 4: Making sense of schizophrenia. This theme can be defined as caregivers' attemps to understand various aspects related to schizophrenia, events that occur as a result of it, and attempts to gain insight about the situation that carers find themselves in. The theme further marks different behaviours of caregivers, namely, information-seeking (e.g., reading books on schizophrenia); cognitive (e.g., thinking about aspects of schizophrenia); or social interactions (e.g., approaching others that may equip caregivers with an understanding of disorder-related events) directed to reach answers to specific questions about schizophrenia and its caregiving. It should be noted that experiences in this theme are mostly unique to each caregiver, as different caregivers tried making sense of different schizophrenia-related topics in different ways. Lastly, individuals' experiences in this may be subject to change over time as caregivers find explanations for their current unanswered questions or thoughts.

Nine caregivers tried making sense of their experiences in some way or other. Most narratives indicated the caregivers' wish to make sense of the onset of schizophrenia. Caregivers like Skollie provided an example of trying to come to grips with the origin of schizophrenia. In an attempt to gain understanding, Skollie explained that he had approached another for answers. He stated: *"So I said, 'But now, Don, isn't this thing coming from there then? I'm trying to figure it out. Where the hell does this damn thing come from?'"*. Doris explained that she engaged in information seeking strategies, such as approaching her doctor or consulting books to obtain understanding of schizophrenia: *"Nee, nie eintlik nie, eintlik soek ek iemand om my te vertel om my te vertel, my dokter moet my eintlik [pouse] as iemand nie vir my kan, vat ek die boeke dan kyk ek in die boeke [lag]" ("No, not actually, actually I am looking for someone to tell me, to tell me, my doctor must actually [pause] if someone can't, then I take the books and look in the books [laughs]")*.

Suzette made sense of the onset of schizophrenia by assigning its cause to Fred's drug use. She further also created meaning around Fred's behaviour after diagnosis. She discussed this in our interaction:

Suzette: *Kyk, voor Fred die pille gebruik het was Fred 'n baie- hy is oor die algemeen 'n rustige kind gewees, maar toe het hy 'n vriend, hulle vriende onder mekaar het, en nou dagga gerook en- soos hy mos maar gesê het- en toe hy nou gediagnoseer is met skisofrenie, toe is hy nou 'n bietjie aggressief, en- maar nou, hy was nie- en hy's nou nie dat hy sal ons wil seergemaak of so nie, hy- hy was net baie emosioneel.*
Divan: *Emosioneel aggressief emosioneel anderse?*
Suzette: *Hy was- hy was baie- Ja, iewers- hy sal sommer nou huil of so, of- Ja, ek wil net dan sien dat hy staan en huil in die pad, of...*

Suzette: *Look, before Fred used the pills Fred was a very- he was generally a calm child, but then he had a friend, their friends amongst themselves, and smoked weed and- like he said- and when he was diagnosed with schizophrenia, he was a bit aggressive, and- but now, he wasn't- and he's now not that he wants to hurt us or so, he- he was just very emotional.*
Divan: *Emotional aggressive emotional different?*
Suzette: *He was- he was very- Yes, somewhere- he would just cry or so- Yes, I want just want to then see that he's standing and crying in the road, or…*

Theme 5: Fostering the positives. Caregivers held on to positive thoughts to aid coping with the caregiver role. For purposes of this study, I use Caprara and colleagues' definition for positive cognitions (Caprara as cited in Caprara & Steca, 2005). Caprara suggests the term "positive thinking" (Caprara & Steca, 2005, p. 276) which represents thoughts that serve to increase individuals' life-satisfaction, self-esteem, and optimism. Therefore, this theme encompasses narratives that indicate positive thinking or results of this thinking pattern in caregivers. It can further be divided into seven sub-themes that focus on different aspects of positive thinking patterns.

Sub-theme 5.1: Caregiver believes that he/she is doing the best to their ability when providing care. This sub-theme represents narratives where caregivers felt that they were doing the best to their ability when providing care for their relative. Holding on to this belief assisted caregivers in the coping process.

Skollie and Charlie both believed that they were doing their best as caregivers. Skollie stated: *"…maar omdat ek myself nie weet wat is beter nie. Ek moet maar net doen wat ek dink is die beste" ("…but because I myself don't know what is better. I must just do what I think is best")*. Similarly, Charlie also felt that he was doing the best he could as caregiver,

as he had bought a motorcycle for Conrad to use for transport when Charlie was away from home and unable to provide transport: *"Heerder ek probeer ook my bes, ek as sy bike, ek't vir hom 'n bike gekoop nou dat as hy nie gaan dan as ek dan weg is, dan kan hy scooter gebruik, terug heen en weer" ("God I also try my best, when I […] his bike, I bought him a bike now that if he doesn't go when I am gone, then he can use the scooter back and forth")*.

Sub-theme 5.2: Caregiving with confidence. Caregivers who are confident in their role and about their abilities as carer may be a reflection of higher self-esteem. Therefore, this sub-theme includes narratives where caregivers discussed their confidence about their role as carer.

Three caregivers reported that they were confident about their role and abilities as caregivers. Jack spoke with confidence about his ability to overcome challenges posed by caregiving:

> *Yes, it's difficult, but I- I'm a man, mos, so as we are a man you- you get too much challenges in your life, so you must know- know now 'No, I'm going to face this challenge and then I'm going to see over that'.*

Caregivers like Zelda were confident in their role and about their judgements as caregiver. In her interview, she explained how she stood her ground against her husband's criticism:

> Divan: *Laaste vraag, as jy vir die selle ouer moet sê wat het jou deur alles gehelp, wat het jou… ja wat het jou gehelp deur alles waaroor ons vandag gepraat het.*
> Zelda: *Jy moenie laat iemand anders vir jou besluit nie. Iemand anders moet nie vir jou besluit nie. As jy voel my soos 'n ja-broer wees nie, jy moenie ja-broer wees nie. My man het vir my gesê, "Jy… jy moet, jy gaan polies sta-' my koppie was nie vol nie. Ek het nie gespring omdat dit hulle ge trigger het nie. My koppie was nie vol nie.*
> Divan: *So jy moet eintlik in beheer wees van jou eie lewe?*
> Zelda: *Ja, beheer wees hoe jy die situasies opsom. Nie omdat ander sê jy moet dit so… beheer jou eie lewe en kyk, focus, luister wat mense vir jou sê. Luister. Keep it here. Focus. Okay, die een het vir my laas week gesê so wag ek, is nou ja… Okay, nou kyk ek. Luister.*
>
> Divan: *Last question, if you have to tell the same parent what it is that helped you through everything, what you, yes what helped you through everything that we have talked about today?*
> Zelda: *You shouldn't let somebody else decide for you. If you feel me like to be like a*

yes-man, you mustn't be a yes-man. My husband told me, "You… you must, you are going police stat-" my cup was not full. I didn't jump because that triggered them. My cup was not full.

Divan: *So you must actually be in control of your own life?*

Zelda: *Yes, be in control of how you summarise the situations. Not because others tell you you must do so… control your life and look, focus, listen to what people tell you. Listen. Keep it here. Focus. Okay, this one told me last week so I wait, it's yes… Okay now I'm looking. Listen.*

Sub-theme 5.3: Noticing and hoping for recovery. This sub-theme encapsulates experiences where caregivers noticed positive changes in the patient, and hoped for their relative's recovery.

Zuby reflected on the positive changes that have occurred in Peter:

Zuby: *But from what it was, there's been a big, big change, really…Tremendously over the years. I mean, I've been with him now 10 years already. You know, that's when the- this- the research started in coming here to Stikland.*

Divan: *10 years ago?*

Zuby: *10 years ago, ja.*

Divan: *Sjoe, so it's been a journey.*

Zuby: *Ja, it's been a long journey 'til now, but he's able to stand on his own feet and he's for Sister Rieta as well.*

Divan: *Ja, because I interacted with him as well.*

Zuby: *Yes, and you can see straight away. He never used to speak at all.*

Divan: *Mm hm, and that's completely different than the Peter that we see, that I see now.*

Zuby: *That- Ja, very different.*

Zelda voiced how, despite the challenges that her son faced, she was certain that he will recover from the schizophrenia and other life challenges that he encountered:

Oh nee, wat ek vir die wêreld kan sê is, as jy ma is… sal jy nie, jy dink… die ene is goed, daai ene is miskien… nie hy het geval in die lewe, hy het vir homself gery 'n opgelig, daai ene het vooruitstrewend, die ene is nie. Maar, wat maak vir jou dink daai een is beter as die ander ene? Want daar waar daai een geval het, kan hy weer optel. Soos 'n kleintjie as daai kind nou al val, gaan jy daai kind optel, of daai kind as

daai kind vir homself oplig gaat nie oplig nie want hy kan dan nou. Dis die geval van hulle, as hy daar geval het my, my ek sê vir jou Divan, hy gaan weer opstaan. Hy gaan weer.

Oh no, what I can tell the world is that, if you're a mother… you won't, you think… this one is good, that one is maybe… not that he has fallen in life, he has driven himself and picked up, that one is ambitious, that one is not. But, what makes you think that one is better than this one? Because where that one has fallen, he can pick up again. Like a child, if that one falls, you're going to pick that child up, or that child if that child picks himself up you're not going to pick him up because he can. That's the case with them, if he has fallen there my, my I'm telling you Divan, he's going to get up again. He'll do it again.

Sub-theme 5.4: Love towards the person with schizophrenia. This sub-theme comprises the expressions of love from the caregiver towards the person with schizophrenia after diagnosis.

Six caregivers expressed their love towards the patient who they had been caring for. Olivia explained how she and her husband provided caregiving with love and how, as parents, they tried to make their son part of their lives:

Ek sal net vir daai ouer sê kyk net baie mooi na hom, en moet'ie vir hom verstoot nie, gee al jou liefde soos ek en die pa vir hom gee, en al wat hy doen, moet'ie vir hom verwyder nie, gee vir hom wat hy wil hê, want daai's wat ek doen, want dan sê die anders 'Jy moet ophou vir hom so spoil, jy moet vir hom niks gee nie' but as 'n ouer, daarom sê ek maar vir die mense wat sukkel kinders het, kyk maar mooi na hulle, praat met hulle, gee vir hulle baie liefde en so aan…

I will just tell that parent to just look after him well, and don't reject him, give all your love like me and his dad give to him, and everything he does, don't remove him, give him what he wants, because that's what I do, because then the others say 'You should stop spoiling him like that, you shouldn't give him anything', but as a parent, that's why I say to people who have children like that, look after them well, talk to them, give them lots of love and so on…

Zuby voiced a similar experience to that of Olivia. Zuby emphasised her son's disconnection from the world. As a result, she became more protective:

Just show them a lot of love, that's all it is, because they're actually cut off from the outside world in the sense that they're not like a normal person like you and me. I mean, we can communicate; we can talk about any subject. With them it's different, you know… Peter is a good child, and- just- just love them. I would tell you just love them and support them, the main things, support them, love them, show them that you are there for them, you know, and… What else? That's all, that you are there for them.

Sub-theme 5.5: Reflecting with a sense of pride on the person with schizophrenia and having realistic expectations. Caregivers expressed a sense of pride towards the person with schizophrenia. Moreover, caregivers were also aware that their relative was living with a mental illness and, therefore, had realistic expectations about the patient's behaviour. Therefore, this sub-theme incorporates narratives where caregivers reflected with a sense of pride about the patient, while knowing that their relative was ill.

Four caregivers were impressed with their relatives. Here, Maryna reflected how she was impressed by her son when he independently cleaned his room:

Maryna: *Hy sal sy kamer aan die kant maak maar dit sal ook nie wees soos dit moet wees nie maar noudie dag het ek gesien toe lyk dit darem mooi! [beïndruk]*

Divan: *Hmmm! [bevestigend]… So…*

Maryna: *Ek dink dit was verlede week!*

Divan: *Jy klink impressed? [aanmoedigend]*

Maryna: *Ja, toe's ek impressed met sy kamer wat so mooi is, want ek het nie gechange gordyne of niks nie.*

Maryna: *He will tidy up his room but it won't be as it should but the other day I saw and it looked good! [impressed]*

Divan: *Hmm [confirming] … so…*

Maryna: *I think it was last week!*

Divan: *You look impressed? [encouraging]*

Maryna: *Yes, then I was impressed with his room that was looking so nice, because I didn't change the curtains or anything.*

Sub-theme 5.6: Finding gratification in caregiving. Despite the challenges experienced during caregiving; caregivers also reported experiencing a sense of gratification while providing care.

Doris told what a pleasure it was for her to care for her daughter. She attributes this to her daughter's obedience at home: *"...vir my is 'n plesier om vir hulle te [pouse] ek sê altyd, hulle's my juwele [pouse] want hulle's nie daar buitekant soos die ander kinders daar buitekant nie [pouse]... hoe sê mens, gehoorsame kinders." ("...for me it's a pleasure to [pause] I always say, they're my jewels [pause] because they're not out there like the other children out there [pause]... how does one say, obedient children.").*

Sub-theme 5.7: Caregiver personal growth. Caregivers also experienced personal growth in different domains of their lives after becoming a caregiver for a person with schizophrenia. For purposes of this sub-theme, personal growth is defined as an element of psychological well-being that "involves feelings of continued development, seeing one self as growing and expanding, being open to new experiences, seeing improvement in self and behaviour over time, and being able to change in ways that reflect more self-knowledge and effectiveness" (Ryff cited in Leipold, Schacke, & Zank, 2008, p. 203). In this process the person becomes more aware of what is meaningful to their lives, additionally also becoming more caring and connected to others (Hogan & Schmidt, 2002).

Sheila, Betty, Zuby, and Zelda reported aspects of personal growth in their respective interviews. Sheila narrated that she had become more spiritual since being a caregiver and that her strength comes from God. Furthermore, it appeared that she had accepted her status quo and was striving towards living a normal life, despite the challenges associated with being a caregiver. She stated:

> *Like I said, I became more spiritual, more leaning on God for my strength, for my courage you know to carry on and I could feel his presence with me… I felt it, because I could still laugh, I could still be normal, you know?*

Zuby reflected how she had, over time, become more at ease and relaxed since being a caregiver. She further felt that she has also enhanced her interaction with members of her family and that her relationship with her family is now marked with understanding and empathy. She stated:

> Divan: *And since his treatment- I know it's a long time, it's 10 years...*
>
> Zuby: *Ja, it's a long time.*
>
> Divan: *How has your life changed?*
>
> Zuby: *It's changed tremendously. For me also, I'm more at ease, I'm more relaxed. You know, I know he can take care of himself now wherever he goes. You know, we communicate more with each other than we did before. Even his brother also, you*

> *know, we- there was like gaps between all the three of us, we couldn't com- get together to talk, you know- you know, to be as a family, but now we communicate with each other and we know what's going on, and we understand Peter more than what we did before when it started.*

Lastly, Zelda showed characteristics of personal growth during an encounter with another caregiver at a train station. On that particular day, Zelda encountered another mother whose son also lived with schizophrenia. Zelda used this opportunity to educate the other carer about possible healthcare resources that can be utilised to enhance patients' well-being. It seems that Zelda connected emotionally with the other carer and provided a form of support and care to another. She stated:

> *Ek het 'n vrou gekry wat se kind ook skisofrenie dit was jare gelede, het daai kind nooit hospitaal toe gegaan nie…Toe sê ek vir haar kyk hier, gaan en dan vra jy vir die, soos ek netnou vir jou ook gesê het, toe het ek vir haar Suster Retha se nommer gee, en dan loop daai kind ook miskien as hulle nou ge wil het. Toe sê ek kyk hier gaan nou hospitaal toe. Die kind het 'n probleem. Hy't skisofrenie en hulle sal nie vir hom wegwys nie hy moet gehelp word. Want sy't al by hoeveel GPs gegaan, dan betaal sy, ek weet daai mense kan nie vir jou help nie.*
>
> *I bumped into a lady whose child also has schizophrenia, it was years ago, that child never went to hospital… then I said to her look here, go and then ask for this, like I told you earlier as well, then I gave her Sister Retha's number, and then that child will also maybe walk if they wanted to. Then I said look here, go to hospital now. The child has a problem. He has schizophrenia and they won't send him away he must be helped. Because she had gone to how many GP's already, then she pays, I know, those people can't help you.*

Theme 6: Interactional tactics. Caregivers utilised different strategies when interacting with the patient. These strategies aimed at reducing caregivers' anxiety and to avoid creating further stressors in the caregiving environment. Through this means caregivers' behaviours, or at times, carers' abstention from acting served to aid their coping. This theme is divided into two sub-themes that focus on different interactional tactics.

Sub-theme 6.1: Not shouting at the patient. Caregivers avoided shouting at their relatives to facilitate well-being for both. This sub-theme includes narratives where caregivers indicated that they chose not to shout at the patient.

Zelda extensively discussed how she avoids shouting on Mark, as she feels that raising her voice will set-off distress on his side:

> *Jy moenie vir hulle, jy moet vir hulle hanteer… nie op hulle skreeu nie. Jy moet nie vir hulle… Ek weet nie as jy op hulle skreeu, there's something in the mind man that triggers… hulle raak confuse, hulle raak conf- get… 'Moenie, los my net, moenie op my skreeu nie, moenie slreeu nie, praat ordentlik'.*
>
> *For them you mustn't, you must treat them… not shout at them. For them you mustn't… I don't know if you shout at them, there's something in the mind man that triggers… they become confused, they become conf- get… 'Don't, just leave me, don't shout at me, don't shout, talk properly'.*

She continued explaining that while she felt frustrated with Mark, at times, she avoids shouting – shouting made Mark uncomfortable, and she further felt that Mark might feel inferior as a result:

> Zelda: *Jy werk jou op! Jy kry nie uiting nie, jy kan dit nie omdat jy vir hom protect. Soos ek sê ek willie op hom skreeu nie.*
>
> Divan: *En jy weet as jy op hom skreeu gaan dit-*
>
> Zelda: *As ek op hom skreeu, jy kan sien hulle raak so uncomfortable, that sense of [sug]… Loop sommer weg. Jy kan nie, ek het opgelet jy moenie op hulle skreeu nie. Moenie…*
>
> Divan: *Dis baie belangrik.*
>
> Zelda: *Ja… moenie op hulle skreeu nie dit trigger something. They don't like it. Their mind is their own mind. Hulle mind is hulle eie mind. As hy voel hy't daar gevee en dis skoon, dan's dit skoon. Unless you come tell him but in a decent way. Jy kom nie op hom skreeu nie. Jy laat hom nie minderwaardig voel at no cost. Ooit. Praat nie…*
>
> Divan: *So jy moet hom altyd…?*
>
> Zelda: *Mooi. Praat mooi met hulle, hulle gaat nie jou nonsens vat as jy vir hulle skreeu nie. Then you put them in another level.*
>
> Zelda: *You get worked up! You don't have an outlet, you can't do it because you protect him. Like I say I don't want to shout at him.*

Divan: *And you know if you shout at him it's going to…*

Zelda: *If I shout at him, you can see they get so uncomfortable, that sense of [sighs]… walks away. You can't, I have noticed you mustn't shout at them. Don't…*

Divan: *It's very important.*

Zelda: *Yes… don't shout at them, it triggers something. They don't like it. Their mind is their own mind. Their mind is their own mind. If he feels he has swept there and it is clean, then it's clean. Unless you come tell him but in a decent way. You don't come and shout at him. You don't let him feel inferior at no cost. Ever. Don't talk…*

Divan: *So you always have to…?*

Zelda: *Nicely, talk nicely to them, they aren't going to take your nonsense if you shout at them. Then you put them in another level.*

Sub-theme 6.2: Not challenging lack of insight. In order to assist relatives, some caregivers chose not to challenge the relatives' beliefs, and to use strategies such as white lies or going along with misperceptions provided these worked in the relative's favour.

One example of caregivers not challenging the patient's lack of insight was provided by Charlie. He stated that Conrad was in denial about his schizophrenia; however, in order for medication adherence, Charlie told Conrad that the antipsychotic tablets were sleeping pills:

Charlie: *Ja… want in sy, in sy mind [pouse] is hy nie siek nie. Daar's niks fout met hom nie. Want hy glo daar's niks fout met hom nie. [Pouse]*

Divan: *En, so hy sien hom as iemand wat gesond is?*

Charlie: *Ja, hy dink daar, hy's reg daar's nie fout met hom nie… hy kom net hierna toe, hy glo hy kom net hierna toe vir [pouse] pille wat hy moet slaap, en stres, dis wat hy dink is die heeltyd…*

Charlie: *Yes… because in his, in his mind [pause] he is not sick. There's nothing wrong with him. Because he believes there is nothing wrong with him. [Pause]*

Divan: *And, so he sees himself as someone who is healthy?*

Charlie: *Yes, he thinks there's, he's right there's nothing wrong with him… he just comes here, he believes he just comes here for [pause] pills for him to sleep and stress, that's what he thinks it is all the time…*

Theme 7: Being prepared. This theme encompasses various behaviours by caregivers that served to prepare them for patients' demands or for the caregiving role. Caregivers reported that preparations are needed for enhanced coping. Being prepared reduced the intensity of stressors that are created while being a caregiver. After analysis, four sub-themes emerged that illustrate different methods of preparation that were utilised by caregivers in my study.

Sub-theme 7.1: Self-education on schizophrenia. Caregivers engaged in various behaviours to educate themselves about schizophrenia and other aspects related to it that forms part of their everyday lives.

Five caregivers offered accounts of self-education. Sheila explained that she used to read about various illnesses. It appeared, from our interaction, that her better understanding about schizophrenia enhanced her coping at times when Shirley was ill:

> Sheila: *I used to like to read about the [pause] illnesses too, get to understand and get to know it better [long pause]*
>
> Divan: *If you got to know it better what would this mean to you?*
>
> Sheila: *What?*
>
> Divan: *If you had got to know about the illness better, if you understood it better?*
>
> Sheila: *Well, I'm not so- want to know more about it now because [pause] like, I say I went through a lot [pause] I've learned how to cope with it.*

Similarly, Zuby stated that reading and learning about schizophrenia empowered her to handle her situation:

> *I made sure I took out the book at the library on schizophrenia and I read it up, how- it was called 'The ABC of the mind' and I did- I read that up, how the brain works, and that I think also taught me a lot, what I should do and how to handle the situation.*

Sub-theme 7.2: Anticipating the patient's needs in advance. To cope with the demands of caregiving, caregivers acted to prepare for their relatives' needs in advance. One example may be when caregivers had prepared food for the patient before they were hungry or scheduled meal times.

Zelda discussed that she was generally worried at work; since she was concerned about Mark's forgetfulness and that he would forget to turn off the stove. Consequently, Zelda prepared his food in advance. She stated:

> *Ek't dit agtergekom, hulle vergeet in die begin stadium het hy vergeet. Ek moet gekyk het ek was ge worry as ek werk toe gaan. Oh ek hoop nie daai kind sit die stoof aan nie, oh ek hoop nie die kind doen daai nie. En dan het ek op 'n stadium gekom waar ek sommer die burgers gebak het, dan sit ek dit in die fridge, dan bak ek sommer genoeg burgers want ek weet Mark like hy like eet… dan bak ek sommer genoeg burgers en viennas is daar alles is daar maar ek sorg laat dit daar is sodat hy nie 'n plaat kan aansit nie.*
>
> *I noticed that, they forget in the beginning phases he forgot. I had to look was worried when I went to work. Oh, I hope that child doesn't switch the stove on, oh I hope the child doesn't do that. And then I got to a stage where I baked the burgers, then I put them in the fridge, then I'll bake enough burgers because I know Mark likes, he likes to eat… then I'll bake enough burgers and viennas everything is there but I see to it that it's there so that he can't switch on a [stove] plate.*

Olivia explained how she had used a container to allocate her son's antipsychotic medication in advance. Despite this, it appeared as if Alfred displayed poor adherence:

> *Ek sorg altyd laat sy pille van Maandaes tot Vrydaes in'n container is, en hy weet hoeveel moet hy vat, maar hy gaan mos'ie vir my sê hy't nie gevat nie hy gaan vir my sê 'Mammie, ek het gevat', want kyk ek gaan mos nou nie daar wees'ie. Ek gaan miskien nou dag hospitaal toe vir my, vir my afsprake en so aan, en dan as ek terug kom dan sal ek, 'Het jy jou pille gevat?' 'Ja mammie, my' dan gaat kyk ek in die container dan sê ek, jy het dit'ie gevat'ie.*
>
> *I always see to it that his pills from Monday's to Friday's are in a container, and he knows how many he must take, but he isn't going to tell me that he didn't take he's going to tell me "Mummy, I took them", because look I'm not going to be there. I might go to the day hospital for my, appointments and so on, and then when I come back then I will, "Did you take your pills?", "Yes, mummy, my" then I'll go and look in the container then I say, you didn't take them.*

Sub-theme 7.3: Living in the moment. At times, being prepared meant that caregivers had to "live in the moment", synchronising with their current situation and context. This frequently demanded caregivers' immediate responses to situational stimuli, or,

synchronising with the milieu in the caregiving environment. This sub-theme includes narratives where caregivers reported living in the moment as coping agent.

Zuby explained how she tried to identify and empathize with Peter's emotional and psychological state, but also respecting his personal space:

> *If he's on a high I try to also be on a high with him, getting him- getting him involved in whatever I'm doing, or I get myself involved, and when he's on a low then I leave him by himself, then I don't try and interfere in his space, you understand?*

Sub-theme 7.4: Being vigilant. The last behaviour that caregivers engaged in to prepare themselves for the demands of their experiences was to keep an eye on their relatives. Caregivers reported "om die pasient dop te hou" (to keep a watchful eye on the patient) as a behaviour that aided their coping.

Six caregivers stated that being vigilant helped them with caregiving. Betty summarised this sub-theme in her reflection:

> Divan: *En hoe't jy dit deurgemaak?*
>
> Betty: *Ek het hom altyd net ge-watch het, wat was sy next step, waaroor was hy bang. Hy wil nie uit die- uit die deur uitgaan, hy't nie, as hy toilet toe gaan die toilet deur gestaan net oop. Onse toilet is mos so buitekant, ek moet met hom daar staan en wag ek, hy wil nie op sy eise gegaan het.*
>
> Divan: *And how did you make it through?*
>
> Betty: *I always just watched him, what was his next step, of what was he afraid. He doesn't want to go out of the- out the front door, he didn't, if he goes to the toilet the toilet door stays open. Our toilet is outside, I must stand there with him and wait, he didn't want to go on his own.*

Cassey reported a similar experience of being vigilant (dophou), and felt that it helped her to cope with having a child with schizophrenia and the demands of caregiving:

> *Ja, om met die siekte te cope. Ja, om met die siekte te cope. Ek- ek- ek hou vir Chris baie dop. Ek hou vir Chris baie dop, ek praat gedurig met hom saam, ek en hy het staan gesels baie, en- en ek is- en ek is bly toe hy- Ek het baie geworry oor hom toe hy- eventually was hy- was hy so siek gewees dat hy baie- 'n soort van soos sy pa geraak het. Sy pa het- in die laaste jare kon sy pa nie ge-concentrate het op goeters nie, en Chris was ook so, en Chris het 'n- hy was 'n driver gewees.*

Yes, to cope with the illness. Yes, to cope with the illness. I-I-I keep an eye on Chris often. I often keep an eye on Chris, I regularly talk to him, him and I stood chatting often, and- and I am- and I am glad when he- I was very worried about him when he- eventually he was- he was so sick that he was very- type of became like his father. His dad- in the last years his father couldn't concentrate on stuff, and Chris was like that too, and Chris had a – he was a driver.

Theme 8: Cognitive-emotional processes. Caregivers reported various cognitive and emotional processes that contributed to their coping. Therefore, this theme incorporates narratives where caregivers reported either cognitive patterns or emotional experiences facilitated their coping. After analysis four sub-themes emerged that illustrate cognitive and emotional processes.

Sub-theme 8.1: Downplaying the impact of caregiving. Caregivers described how they had down-played the impact of caregiving as a coping mechanism.

Caregivers commonly downplayed two experiences. First, caregivers downplayed their perceptions of the patient – if the patient fell into the *easy* or *difficult patient* category. Second, caregivers de-emphasised the demands that being a caregiver introduced to their lives.

Maryna downplayed that Martin was a problem at home, but at the same time she also stated that he had displayed verbally abusive behaviour: *"Hy's nie meer moeilik nie, hy was nou hier onlangs na dit, wat hy uit die hospitaal uitkom wat hy nou so begin te stap gewys, so reggop, het hy so begin te vloek in die nag! [geskok]" (He's not difficult anymore, he was here now shortly afer that, when he came out of hospital where he started to walk in a way, upright, he began to swear at night! [shocked]").*

She also underplayed her experiences about her son's room: *"Hy sal sy kamer aan die kant maak maar dit sal ook nie wees soos dit moet wees nie maar noudie dag het ek gesien toe lyk dit darem mooi! [beïndruk]" ("He will tidy up his room but it also won't be like it should be but the other day I saw and it looked very nice! [impressed]").*

Betty de-emphasised the demands of caregiving and her perceptions of Brett:

Die uitdagings sal ek sê nee, ek sal nie sê ek het kwaai uitdagings het met Shahid nie, maar ek het net vir hom gesê hy moet net vat sy pilletjies, doen net wat Mammie sê en "Luister wat ek vir jou sê," en soos ek nou voel op die oomblik, wat ek vir hom nou sê, "Moenie so rondloop nie." Okay, hy hou van rondloop. Hy hou van rondloop, van visit, en dan sê ek ook- heune, sy "Jy kom weer laat in. Jy moet dan môre oggend..."

soos hulle oggend beken, met die klein kinders, "Môre moet jy weer vroeg opstaan," en hy was al klaar gisteroggend vroeg by die hospitaal maar hy kom nog altyd eleven o'clock in die aand. Toe sê ek "Raak jy dan nie moeg nie?" nou word net hy, as hy rondloop nou wil hy te rus, as hy sien kans wil hy rus.

The challenges I will say no, I won't say I have intense challenges with Shahid, but I just told him he must just take his pills, just do what Mummy says and "Listen to what I tell you," and like I am feeling at the moment, where I tell him now, "Don't walk around like that". Okay, he likes walking around. He likes walking around, visiting, then I also say- […] his "You are coming in late again. Tomorrow you have to…" as their morning […], with the small children, "Tomorrow you have to get up early again," and yesterday morning he was already at the hospital early but he still comes in at eleven o'clock at night. Then I said "Don't you get tired?" now just he becomes, when he walks around he wants to rest, if he is up to it he wants to rest.

Doris appeared to reduce the negative impact caregiving had on her health. Her laughing might suggest some anxiety that she experienced during this discussion. Alternatively, her laughter may be a way of downplaying the impact that caregiving had on her health. She stated: *"Nee, niks verander nie, dis dieselfde [lag] nou's ek ook siek! [lag]" ("No, nothing changes, it's the same [laughs] now I'm also sick! [laughs]")*.

Sub-theme 8.2: Avoidance. Caregivers further utilised avoidance as a cognitive process for coping. Avoidance can be defined as the act(s) of keeping away from situations, environments, people, or objects. Acts can be attributed to either: 1) the anticipated negative consequence of such an encounter; or 2) anxious or painful feelings that result from the encounter (VandenBos & APA, 2015). Therefore, avoidance can be regarded as a person's mental or emotional actions directed at escaping negative or distressful experiences.

Caregivers displayed avoidance in two domains. First, caregivers avoided confrontations that might induce conflict between themselves and their relative. Second, caregivers also avoided distressing thoughts that arose from being a caregiver or being in the caregiving setting, and about their relative's schizophrenia.

Betty explained how she had avoided verbal confrontation with her son:

Hoe sal ek sê, as ek miskien- as hy nou iets gedoen het wat my kwaad gemaak het, né, dan sal ek dit nie uiter, verstaan, ek was maar 'n ene wat alles hier binne; ek praat maar eerder bokant toe, as wat ek uit sê. Dis daai dinge wat ek diep inhou.

> *How will I say, if I maybe- if he did something that made me angry, né, then I won't say it, understand, I was one that everything inside; I rather talk upwards, than saying it out loud. It's those things that I keep deep inside.*

Similarly, Natalie stated that she avoided verbal confrontations with her brother; as a result conflict was diminished:

> *Nee nee daar's nooit 'n bakleiery daar nie, nooit 'n bakleiery nie. Omdat ons altyd mos maar [pouse] en sometimes as hy dinges praat en sê dan hou ons maar almal onse mond, you know? Dan hou ons maar almal onse mond.*
>
> *No no there's never a fight there, never a fight. Because we always [pause] and sometimes when he talks things and says then we all keep our mouth, you know? Then we all keep our mouth.*

Lastly, Charlie reported that, while he disagreed with the statements his son had made, he avoided challenging his son's stories:

> *Hulle praat baie oor die verlede, soos ek gesê het, baie oor die verlede uit dan dink jy maar [pouse] maar wanneer hy oor die verlede en sulke goed praat, al wat ek sê net is, ja. Ek stem net saam… maar ek sê nie vir hom, jy praat nou nonsens nie… ek wil nie dit want dan gaan hulle [pouse] baie upset raak as jy nou vir hulle sê dit het daai tyd nie gebeur nie, jy bly maar net stil, jy weet wat dit, waaroor dit gaan…so jy jy gaan nie vir hom [pouse] jy gaan nie [onduidelike audio]… sê, right hou op oor nonsens praat en hou op dit, ek [pouse] en ek in jou mind sê jy, ag praat maar…dis wat ek doen.*
>
> *They talk about the past, like I said, a lot from the past then you think but [pause]but when he talks about the past and stuff like that, all that I just say is yes. I just agree… but I don't tell him, you're talking nonsense now… I don't want that because then they [pause] become very upset if you tell them now that didn't happen that time, you just keep quiet, you know what it, what it's about… so you you are not going to [pause] you are not going to [inaudible audio]… say, right stop talking about nonsense and stop that, I [pause] and me in my mind you say, ag just talk… that's what I do.*

Four caregivers avoided distressing thoughts related to their experiences as carer.

Doris avoided considering the possibility that her daughter was still ill: *"Maar Dawn is vir my gesond, want sy tree normaal op, is net party dae wat sy weer goeters sien is al…" ("But Dawn is healthy to me because she behaves normally, it's just some days that she sees things again that's all…")*. Similarly, Suzette reported traits of avoidance: *"Somtyds dan voel dit vir my dat Fred het nie skisofrenie nie…" "Sometimes it feels to me that Fred doesn't have schizophrenia…").*

Sub-theme 8.3: Acceptance. For coping, caregivers also accepted their situations on an emotional level. Acceptance is defined as a person's willing acknowledgment of validity or unchangeability of a situation. In the context of being a caregiver this may suggest that caregivers acknowledge or come to terms with their status quo. After this, constructive changes in their lives or coping mechanisms might be facilitated. Therefore, this sub-theme includes narratives where caregivers provided examples of acceptance as a coping mechanism.

Five caregivers reported accepting their experiences and situations. For Betty, it was important to accept her son's schizophrenia, as this was the first challenge she had to face as a caregiver. She stated: *"Kyk jy, né, wanneer mens aanvaar, dan kom jy uit jou streke uit, want ek meen my eerste ding wat ek nie deurgemaak het, ek kon nie gekoppel het nie, ek het geaanvaar" ("Look you, né, when one accepts, then you come out of your mannerisms, because I mean my first thing that I didn't make through, I couldn't link, I accepted")*.

When Doris accepted the possibility that schizophrenia is a heritable illness and not a punishment for sins she had committed, she experienced relief:

> *Soos ek maar altyd sê, is nie 'n sonde nie [pouse] ek sê in die begin is dit moeilik, dan dink jy die mense is dalk [pouse] dat hulle iets vir jou, iets sleg vir jou sê, of so, dan't ek altyd gesê jy moet maar, jy gaan daar uitkom…jy kyk 'n persoon vas in die oë, want dit is nie 'n sonde om daai siekte te hê nie…Want as jy eers gehoor, wat jy nie daaroor, hoe sê mens, jy't nie gemaak daai siekte nie…jy's nie verantwoordelik vir daai siekte nie…dit het maar net gebeur, dis al. Of hulle sê is 'n familie erfenis…ek het aanvaar, vir my dink ek nou net ek sou die persoon vas in sy oë kyk…dan sal jy nie voel jy kry so ruk, jou hart slat jou so'n ruk gee is al, dan dink jy net by jouself…dis nie 'n sonde nie…*
>
> *As I always say, it's not a sin [pause] I say in the beginning it's difficult, then you think the people are maybe [pause] that something for you they, say something bad to you, then I always said you must, you are going to get out of it… you look that person*

> *right in the eye, because it isn't a sin to have that illness… Because when you've first heard, what you don't about it, how does one say, you didn't make that illness… you aren't responsible for that illness… it just happened, that's all. Or they say it's a family heredity… I have accepted, for me I think now that I will just look the person straight in the eyes, then you won't feel you get such a jolt, your heart hits you such a jolt is all, then you just think to yourself… it's not a sin…*

Sub-theme 8.4: "We got strength to carry on". Caregivers attributed the capacity to cope with the demands of caregiving to their emotional strength. Therefore, this sub-theme represents caregivers' accounts of drawing on their strength in order to cope with their experiences.

Four caregivers felt that they were emotionally strong. Cassey summarises this sub-theme when she perceived herself as an emotionally strong woman: *"Dit- dit help vir my om net sterk te wees, om net sterk te staan, en as- en enigiets wat ek- wat ek ge- wat gebeur- en laat ek- laat ek sterk wees daaroor" ("It- it helps me to just be strong, to just stand strong, and if- anything that I- that I- what happens and I let- let me be strong for it")*. Interestingly, she reported how Chris' sister also reflected Cassey's strength:

> *Ek sou nie sê daar is enigiets wat ek gebruik nie, dit is maar net as mens is ek so, as ek in 'n krisis in dan is ek so, en...So Sally het verjaar Junie maand, wanneer sy gevisit verlede jaar, en toe gee my suster haar haar partytjie, en toe sê sy "My mom was 18 years old when she..." dinge, "and life has changed, that time when I was born, and she was- she's the best mom, and she's a strong mom, she's a brave mom."*
>
> *I wouldn't say there is anything that I use, it's just when one, I am like, if I am in a crisis then I am like that, and… So Sally celebrated her birthday in the month of June, when she visited last year, and then my sister gave her her party, and then she said "My mom was 18 years old when she…" things, "and life has changed, that time when I was born, and she was- she's the best mom, and she's a strong mom, she's a brave mom."*

Theme 9: Professional healthcare services. Caregivers approached and accepted assistance from professional healthcare services to assist them with the demands of caregiving. This also made their lives easier during challenging times. Professional healthcare services include, but are not limited to, individuals (e.g., doctors, nurses,

psychologists, and social workers); and institutions (e.g., clinics, hospitals, schizophrenia-care centres) that provide physical or mental healthcare. Thus, this theme encompasses narratives where caregivers indicated professional healthcare services as coping facilitators.

These services made caregivers' lives easier by various means such as providing antipsychotic medication and specialised mental healthcare, and caregivers could admit patients to institutions for observation during acute psychotic phases.

Nine caregivers spoke about the assistance with which healthcare services complement their role as carers. Moreover, caregivers also felt that healthcare resources functioned to improve the well-being of their relative with schizophrenia.

Cassey took Chris to the doctor in an attempt to calm her worry: *"sy suster het ook huis toe gekom en sy was ook bekommerd, en ons het- toe saam met ons vir hom by die dokter gekry en so aan" ("his sister also came home and she was also worried, and we did- along with us got him to the doctor and so on")*. Next, Betty voiced how Brett's mental health improved after he attended Stikland Psychiatric Hospital. She stated: *"Yes. Maar kyk jy hier, hy raak nie eintlik much siek geword vandat hy by Stikland in die dag gekom het" ("Yes. But look here, he doesn't get much sick since he came to Stikland in the day")*.

Jack stated that his approach to increase the chances of Jessica's well-being is to take her to a doctor:

> *No, you know mos, every- even- even you know, maybe it's not here when someone is not- is not all right you can't feel happy, you see, so you have to make a plan to- to get her some doctor or any- or any help, you see.*

Charlie discussed how his son's schizophrenia was assessed by a psychiatrist. The psychiatrist further initiated antipsychotic treatment with Conrad. Lastly, Charlie explained how the psychiatric treatment also incorporated a patient-friendly treatment plan with Conrad. His discussion follows:

> Charlie: *toe sê hulle hy't skisofrenie, toe begin hy kom, daai tyd, toe begin hy kom na 'n dokter [pouse] X, sy't hom, sy was die eerste persoon wat hom eintlik begin behandel het…so van daar af het hy begin… en toe sê hulle hy moet op hierdie pille gaan, en dis hoeveel jaar nou, is hy op daai pille…*
>
> Charlie: *Then they said he has schizophrenia, then he began to come, that time, then he began to come to a doctor [pause] X, she, she was the first person that actually started to treat him… so from there on he started… and then they said he must go on*

these pills, and that's how many years now, he is on those pills…

Charlie continued:

Divan: *En wat doen dokter X hulle anderste as die ander dokters?*
Charlie: *Want sy gesels mooi met hom, sy praat met hom, en sy kan hom goed handle, soos ek sê… en sy praat mooi met hom en sy [pouse] sy gaan regtig uit om hom te help…so hy hou daarvan. Jy moet hom 'n bietjie prys ook…Dis wat my sussie ook sê, prys hom, gee vir hom 'n reward, sê dankie Conrad vir wat jy gedoen het, sulke goed…*

Divan: *And what does doctor X and them do differently than the other doctors?*
Charlie: *Because she talks nicely to him, she talks to him, and she can handle him well, as I say… and she talks nicely to him and his [pause] she really goes out to help him… so he likes that. You must praise him a little too… that's what my sister also says, praise him, give him a reward, say thanks Conrad for what you have done, stuff like that…*

Lastly, Zuby explained about the psychoeducation that she received from a psychiatrist. This played a key role in her understanding of the schizophrenia:

But he wasn't like that, he was living in his own little world, and we tried to break through that world of his. So both of us came here to Dr. X also in the beginning, you know, to find out what it's all about, how to handle Peter. We spoke about Peter's doings as well, and "Go back home and try..." You know, put the puzzle together and see where we can try and help him as well from our side, and trying to understand what he's going through.

Theme 10: Lay-care services. Caregivers also relied on lay-care services to assist them with the demands of caregiving. Lay-care services may be defined as any service – person or institution – that are not formally qualified to provide specialised care to a person with a mental disorder. An example of a lay-care resource may be a nanny who provides the caregiver with assistance with the caregiving task.

Four caregivers utilised lay-caregivers to assist them with the caring for their relative. Interestingly, most lay-carers were family members who stood in for caregivers when they

were not able to attend to the patient. Betty told how her sister assisted her with caregiving on days when Betty had to work:

> *Okay, vir my was dit "Ek werk, hoe gaan ek agter die kind kyk? Daar moet 'n mens- daar moet iemand vir hom wees." Gelukkig my suster het nie gewerk nie want sy het die twins en hulle het nog klein gewees het daardie tyd. Sy moet nog by hulle bly vir 'n tydperk en sy het toe maar opgepas.*
>
> *Okay, for me it was "I work, how am I going to look after the child? There must be a person, there must be someone for him." Luckily my sister didn't work because she has the twins and they were still young that time. She must still stay with them for some time and so she took care.*

Theme 11: Police services. Caregivers reported that they made use of police services during difficult times. This theme includes narratives where caregivers stated that police services contributed to their coping.

Cassey reflected how the police pressured Chris to initiate his antipsychotic medication: *"Toe kom die polisie vir hom haal om op medikasie te gaan" ("Then the police came to fetch him to go on medication")*. Similarly, Doris stated that the police took her daughter to the hospital: *"Die polisie het vir haar verlede jaar kom haal en vir haar geneem hospitaal toe" ("The police came to fetch her last year and took her to hospital"*). Lastly, Zelda explained that her husband was more at ease after she had obtained a restraining order via police through the court:

> *Weet jy my man is nie meer van nadat ek die interdik gekry het, hy… ek dink hy was ook meer stressed. Hy's dan nou die… hy kom in hy stres hy's nie nou so tense nie. Hy's nie meer so tense nie want ek het nou 'n step gedoen.*
>
> *You know my husband isn't […] anymore since I got the interdict, he… I think he was also more stressed. He's now the… he comes in he stresses he's not so tense now. He's not so tense anymore because I made a step now.*

Theme 12: Financial support. Financial support also assisted caregivers to cope with the demands of caregiving and the alleviating possible financial burdens introduced after the schizophrenia diagnosis. For purposes of this theme, financial support only includes finances that are received from non-social support agents (as described in the next theme).

Therefore, this theme includes narratives that indicated financial support from, mostly; government based or privately owned organisations.

Skollie discussed the assistance that belonging to a medical aid offered him. It appeared that the financial assistance that he received reduced his stress about financial difficulties:

> *As ek blootgestel aan die publieke hospitale- Kyk ek is ǹ- ek is ǹ- ek is ǹ pensioenaris van die Stadsraad, en deel van voordele as jy het vroeër jare gedien het, dan kry jy ǹ- dan betaal jy het ǹ derde mediese fonds, hulle betaal die ander twee derdes, so ek betaal, ek het begin in 2007 toe het ek nou op pensioen gegaan. Toe was dit R784, dis nou R1868… Good Lord. Thank God I'm in a medical aid, for how long I don't know. Gelukkig ek behoort aan ǹ pensioen fonds.*
>
> *If I am exposed to the public hospitals- Look I am a- I am a – I am a pensioner from the City council and part of the advantages if you served in earlier years, then you get a – then you pay you have a third medical aid, they pay the other two thirds, so I pay, I started in 2007 then I went on pension. Then it was R784, it's now R1868… Good lord. Thank God I'm in a medical aid, for how long I don't know. Luckily I belong to a pension fund.*

Theme 13: Social support. Caregivers initiated or accepted social support resources to increase their sense of well-being and facilitate their coping during difficult times. Social support can be defined as:

> the provision of assistance or comfort to others, typically to help them cope with biological, psychological, and social stressors. Support may arise from any interpersonal relationship in an individual's social network, involving caregivers, family members, friends, neighbours, colleagues, or support groups. It may take the form of practical help (e.g., doing chores, offering advice), tangible support that involves giving money or other direct material assistance, and emotional support that allows the individual to feel valued, accepted, and understood (VandenBos & APA, 2015, p. 1001).

Social support for caregivers was obtained mainly from four different interpersonal relationships. First, and most common, caregivers obtained social support from family members. Second, social support was offered by caregivers' friends. Third, relationships

with colleagues supported caregivers. Lastly, unspecified community members also provided caregivers with a sense of social support. Examples each are provided:

Cassey discussed how she had found comfort when she phoned Chris' sister after a challenging interaction with him:

> *Ek was so ontsteld, ek het gaan lê op my bed, ek het so gaan- want hulle nou ry, toe-then- toe bel Bella vir my dogter, toe sê ek vir haar "Wat het nou gebeur?" en toe sê ek vir haar "Ek gaan nou- ek wil nou eers 'n bietjie rus want ek is so onstelt ek sal dit nie nou kan doen. Ek gaan net so 'n bietjie lê, ek gaan nou polisie toe" sê ek vir haar. Toe sê sy ja, okay, ek moet gaan. Ek moet gaan.*
>
> *I was so upset, I went to lie on my bed, I went like- because they drive now, then-then- then Bella phoned my daughter, then I said to her "What happened now?" and then I said to her "I am now going- I want to rest a bit first because I am so upset, I won't be able to do it now. I am just going to lie down a bit, I am going to the police now" I said to her. Then she said yes, okay, I must go. I must go.*

She added: *"…en ek het 'n dogter- ek het 'n dogter wat baie caring is, sy's sane, sy's baie caring oor my, sy bel my gedurig" ("…and I have a daughter- I have a daughter who is very caring, she's sane, she's very caring over me, she calls me regularly")*.

Doris reflected how her extended family stood by her during the time her children became ill with mental disorders:

> *Nee daar't my 'n…'n Richard se sisters, my ma en, hoe sê mens dit, Reggie se susters en ma…en my susters, hulle was daar vir my gewees, toe hulle siek geraak het. Dan was hulle daar. Tot nou nog toe is hulle my familie.*
>
> *No there […] me a… a Richard's sisters, my mother and, how does one say it, Reggie's sisters and my mother… and my sisters, they were there for me, when they got sick. Then they were there. Until now still they are my family.*

Charlie stated how he had found pleasure in interactions at his friend's house: *"As ek na my vriend toe gaan, ons praat oor die ouderdom, ons praat oor baie goed, daar's daar's altyd iets interessant en iets nuuts, watookal" ("When I go to my friend, we talk about the age, we talk about many things, there's there's always something interesting and something new, whatever")*.

Zuby explained that she did not have many friends where she stays, but that she

confides and finds comfort in conversation with a colleague at work. By talking to her colleague Zuby reduced the distress she experienced. She stated:

> *I don't have much friends at home, except for the neighbours that we have across the road. I mean, most of the time I'm at work so I only get home in the evening, weekends I see them now and then. Okay, they're housewives, you know. And the friends that I've got at work knows about Peter's situation as well. I've got a very close friend that I work with, my colleague. Her name is June. She knows about Peter's situation so if there's anything that's bothering me we talk about it, you know, I talk, and she tries and helps, in her own little way tries to understand, you know.*

Lastly, community members also offered social support to caregivers. Caregivers commonly spoke about members of the community and how these individuals had played a "social informant" role. Members of the community kept a watchful eye on the patient when caregivers were not present. Moreover, members of the community informed caregivers of the whereabouts and behaviours of the patient. It may appear to the reader as if the caregiver reported being feeling visible or ashamed that others noted the patient's odd or problematic behaviour; however, in the context of the interviews this was perceived not to be the case. Betty expressed a sense of thankfulness and relief when others had kept a watch eye on Brett. She provided an account of where people phoned her at work, updating her about her son's behaviour:

> *At work, dan phone die mense vir my, hulle sê miskien vir my "Brett het nou daai gedoen. Wat makeer Brett, is Brett siek? Weet julle dat hy siek is?" Dan sal ek altyd sê "Ja, ek weet." Ek hou hom dop maar hy doen nie die dinge voor my nie, hy doen dit miskien buitekant maar by my, deny hy dit, verstaan jy?*
>
> *At work, then the people phone me, they maybe say to me "Brett did this now. What's wrong with Brett, is Brett sick? Do they know that he's sick?" The I will always say "Yes, I know". I keep an eye on him but he doesn't do the things in front of me, he maybe does it outside but with me, he denies it, you understand?"*

She continued: *"Ander mense sien dit, maar hulle bring- hulle kom sê dit vir my of hulle phone my, of sit op die Facebook vir ons om te kan sien en so aan" ("Other people see it, but they bring- they come and tell me or they phone me, or put it on Facebook for us to see and so on").*

This chapter reported the findings that emerged after data analysis. It should be noted that the role of caregiver is unique for each individual. This is because different caregiving situations cause different reactions from carers, as the demands of caregiving also differ. Factors such as caregivers' and the patient's age, the gender of the caregivers and patient, their culture, their socioeconomic background, all influence the burdens and coping mechanisms that caregivers experience (Gutiérrez-Maldonado et al., 2005). Apart from the experiences of burden and coping that were explored in this chapter each caregiver also had experiences particular to them – unique burdens and coping mechanisms. However, the goal of this chapter was to present caregiver burdens and coping mechanisms that were shared by carers in my study. The next chapter discusses the findings above by drawing on existing literature in the field, but also reports novel findings from my study. Thereafter, Chapter Six concludes by exploring the strengths of and limitations to, my research and recommendations are provided for future research in the schizophrenia caregiving domain.

CHAPTER SIX

DISCUSSION AND CONCLUSION

Caregiving in the context of schizophrenia is complex and challenging. It also takes place in the context of other aspects of caregivers' lives. The caregivers I spoke with in this study reported some experiences which have been reported elsewhere in the literature, but each story is unique and in interaction with the small number of people I spoke with, I gained new insights.

As with the work of Molefi and Swartz (2011), my study contextualised caregiving and related caregiver experiences within the Western Cape. Therefore, it is important to compare my study with other literature on care in the context of schizophrenia – to point out similar experience, but also to produce additional information that may contribute to others' understanding of caregivers' experiences. Therefore, this chapter discusses the findings of my study by contextualising my findings in the literature reviewed, but it also goes beyond this when it interprets novel experiences that were reported.

As my study explored two components of caregivers' experiences – 1) caregiver burden and 2) caregiver coping, this chapter discusses these independently. Thus, the chapter is divided into two sections and will discuss some of the themes that emerged in these two domains of caregiving.

Before discussing caregiving burden and coping, I need to emphasise that I studied only caregivers' accounts of living with a person with schizophrenia. I did not observe or measure in some other way actual caregiving interactions. Nor did I observe or speak with the person with schizophrenia (apart from obtaining informed consent). Although it is crucial to acknowledge the limitations of self-report by single parties in caregiver interactions, it is also not unreasonable to assert that actual caregiver experiences must have influenced experiences of burden and coping and hence reports of burden and coping. Thus, though I cannot verify the accuracy of reports of the person with schizophrenia, the discussion will draw on some experiences that were reported in *caregivers' description of the person living with schizophrenia* to facilitate the discussion of caregiver burden and coping.

Caregiver Burden

Caregivers' experiences of burden were conceptualised through the Objective and Subjective Burden of care perspective (Awad & Voruganti, 2008). Moreover, my study also explored

what I termed *Caregiver's contextual challenges* – challenges that caregivers experienced apart from the challenges that were introduced when having to provide care for the person with schizophrenia at home. I use the issue of contextual challenges to provide a framework within which to understand issues more directly to do with caring for a person with schizophrenia.

Contextual Challenges

Age and gender. The median age of participants was 58 years; the majority of caregivers were aged 58 years or older. This age pattern in caregivers conforms to local finding by Negota and Mashegoane (2012). As in the local work by Mhaule and Ntswane-Lebang (2009), and abroad by Saunders and Byrne (2002), the caregivers in my study were predominantly female and were mothers of a child with schizophrenia. According to Gutiérrez-Maldonado et al. (2005), mothers are more likely to be tasked with caregiving and experience the greatest caregiver burden. A plausible explanation may be that in many cultures it is the norm for women to stay at home and attend to chores and raise their children, while the men are at work earning an income. Caregivers like Maryna and Skollie voiced that caregiving was usually the woman's responsibility at home.

While caregivers' age might appear to be unrelated to schizophrenia caregiving, it added to the challenges associated with this role. Many caregivers reported that their age made it difficult for them to provide care for their relative. It may not always be an easy task for caregivers of age to handle their relative's problematic behaviour, or to meet the demands of the new activities (e.g., attending multiple doctor appointments; or actively keeping a watchful eye on the patient) that are introduced by the caregiver role (Mhaule & Ntswane-Lebang, 2009). The reality that many caregivers are alone in this role, with limited social support, may further exacerbate this aspect of caregiver burden.

Also, the majority of caregivers in my study were at an age where it is normally expected for their children to have left the house and live independently; caregivers like Charlie indeed voiced this expectation. However, all patients were still living with their caregivers. Consequently, many caregivers may have experienced a life cycle squeeze – the situation where one's "resources are inadequate to meet the needs engendered by the number and ages of his [their] children" (Duncan & van Niekerk, 2011; Oppenheimer, 1974).

Personal health challenges. Besides providing care for a relative with a complicated mental disorder such as schizophrenia, caregivers also had to consider their own, and the

patient's physical health (Bauer et al., 2012). The majority of caregivers reported that they had experienced personal mental and physical health difficulties. Interestingly, some caregivers' health challenges had its onset after they took on the caregiver role – it is possible to assume that caregiving took its toll on the mental and physical well-being of caregivers (Bauer et al., 2012). While it was outside the scope of my research question, it is possible to assume that caregivers not only had to witness schizophrenia illness related behaviours, but also had to endure experiences introduced by their own illness. As with old age, personal health conditions may introduce its own burden to caregivers, which may further complicate and intensify challenges in the caregiver role. It was also common for caregivers to have cared for more than one person with schizophrenia; or with an alternative physical or mental illness.

It appeared as if diabetes was an illness shared by caregiver and patient. My study provides a possible explanation for this occurrence. Environmental factors such as obesity, over-nutrition and physical inactivity have been identified as risk factors (Luley, Blaik, Reschke, Klose, & Westphal, 2011). Caregivers may have characterised some of these environmental factors such as physical inactivity (e.g., not being able to exercise) due to their commitment to the caregiving role. Moreover, caregivers commonly reported physical inactivity (e.g., excessive sleeping) and over-nutrition (e.g., increased appetite) in patients as a side effect of antipsychotic treatments.

Lack of knowledge about schizophrenia. Local literature has explored caregivers' lack of knowledge about schizophrenia (Kotze et al., 2010; Motlana et al., 2004). It was therefore no surprise when caregivers of my study reported similar accounts. Caregivers' lack of knowledge may be regarded as exacerbating other challenges that are experienced, before or after their relative's diagnosis. Particular focus can be assigned to caregivers' emotional experiences of uncertainty, and guilt. Caregivers struggle daily to gain a better understanding, particularly with regard to the origins of the disorder, and the consequences of having this disorder. Due to this, caregivers may experience guilt, as they do not fully understand factors that contribute to the onset of schizophrenia.

My findings suggest a need exists for the enhanced distribution of accessible and easy to understand information and education about schizophrenia, and the importance of proper communication between caregivers and schizophrenia-care professionals (Motlana et al., 2004). It was interesting to hear that caregivers regarded the negative symptoms of schizophrenia (e.g., isolation, and passive lifestyle), as recovery hindering factors. One may argue that had caregivers known enough about schizophrenia and its repercussions on the

patients, they would have been able to distinguish these symptoms from recovery hindering factors. A body of literature exists that argues the effectiveness of psychoeducation as intervention for caregivers of people with schizophrenia (Asmal et al., 2014; Birchwood & Smith, 1987; Cassidy et al., 2001; Kritzinger et al., 2011; Lim & Ahn, 2003). Locally, Asmal et al. (2014) have reported on the value of psychoeducation for caregivers of people who experience psychosis. In their intervention, Asmal and her colleagues (2014) specifically focused on educating caregivers regarding the biology behind the patient's psychotic experiences, side effects of anti-psychotic medication, communication techniques, and problem solving and crisis management strategies. Caregivers who participated in my study expressed a desperate need to empower themselves with the knowledge that can be obtained through interventions such as that of Asmal et al. (2014). Interestingly, psychoeducation on schizophrenia is an acceptable and feasible method of intervention in many African contexts (Asmal et al., 2014). Moreover, healthcare professionals can play a fundamental role in clarifying, not all, but, many uncertainties that caregivers experience because of their lack of knowledge of schizophrenia. Yet, participants reported that, at times, clinicians did not regard their concerns important or as urgent. As a result, important information that may alleviate caregivers from their experiences of burden is not at all or only partly disseminated. There is a caveat here, though. Information-giving and information-receiving is a two-way process and it may be that people have been given information which they have not been able to hear or accept – in fact in one case, one of my participants, whose relative was part of a schizophrenia research project and who had read and signed consent forms about this, expressed shock and surprise that the relative had schizophrenia. Clearly, it is not enough to call for more information for relatives – a careful study of different methods of giving information, and testing what is retained at follow-up, is important in the African context.

Drugs in the community. One of the most common day-to-day challenges that added to the complexity of schizophrenia caregiving was the availability of drugs, and particularly cannabis, in the community. This could have been expected, as cannabis has, in the past, been regarded as one of the most frequently recognised drug of abuse in South Africa (Parry et al., 2004); this pattern of substance abuse or misuse may also be the case today and in the patients of this caregiver sample. Against this backdrop, it has now been well established that drug use, and in particular that of cannabis, is a risk factor for psychosis and schizophrenia (Cannon et al., 2008; D'Souza et al., 2005; Hambrecht & Häfner, 1996; Kristensen & Cadenhead, 2007; Morrison et al., 2009). It was, therefore, interesting to note

that caregivers, as well, attributed the onset of their relative's schizophrenia to drug use (Motlana et al., 2004).

Caregivers reported that difficult patients are commonly characterised by substance abuse and easy patients by its abstinence. In their work, Kolliakou et al. (2011) discuss possible reasons for patients' co-occurring substance abuse while living with psychosis. It appears that patients may use cannabis as a form of self medication to reduce the distressing moments that are caused by the schizophrenia (or prior to the onset of the psychosis to treat prodromal symptoms) (Khantzian, 1985, 1987, 1997; Kolliakou et al., 2011). This was confirmed by caregivers like Charlie when we discussed his son's drug use habits: *"dis soos'n toevlug vir hom…" ("it's like a refuge for him…").*

While self-medicating, patients may initiate a dreadful vicious cycle. Cannabis consists of two compounds: 1) cannabidiol (CBD), and 2) Δ^9- tetrahydrocannabinol (THC). On the one hand, the CBD molecule is able to relieve psychotic states (Waldo Zuardi et al., 2012). On the other hand, it is the THC molecule, which mainly dominates cannabis' effects on humans, that has been shown to trigger psychotic states (Waldo Zuardi et al., 2012). Therefore, it seems that patients who use cannabis may battle to escape a substance induced psychotic state. A conundrum is created however. If we argue that patients self-medicate with cannabis in an attempt to alleviate their schizophrenia symptoms, but, at the same time, are unable to escape psychosis – one may question the actual reason for patients' drug use. A plausible explanation may be the anxiolytic effects of cannabis on humans (Schier et al., 2012). My findings suggest that, as Charlie stated, patients *run to* cannabis in an attempt to calm their anxieties created by the schizophrenia.

However, the patient's drug abuse had widespread repercussions on caregiving. First, the patient was exploited for other drug users' personal gain. Second, it induced aggressive and destructive behaviour in the patient. Third, caregivers further felt that cannabis use hinders the recovery of patients.

Experiences of Objective Burden

The participants in my study reported various objective burdens after they had taken on the caregiving role. It appears that for most caregivers the objective burdens were created by having to care for their family member at home, i.e., caregivers may not have reported these burdens if the patient had been permanently institutionalised after diagnosis. Experiences of

objective burden were encapsulated by at least eight themes or sub-themes in Chapter Five. These themes include:

1) new activities for caregiver;
2) physical strain on caregiver;
3) the effect on the caregiver's social environment;
4) patient's problematic behaviour;
5) distressing experiences caused by having the illness;
6) patient dependency;
7) disruption; and
8) difficulties experienced at healthcare services.

New activities and physical strain. When the person becomes a caregiver, or continues as a parental caregiver, but now in the context of schizophrenia, there may be new or intensified caregiving activities. These include, cleaning the patient's living space, doing extra shopping to provide for the patient, doing the patient's washing, and helping to maintain the patient's hygiene – activities beyond what would generally be expected for the care of an adult. There were four activities, specific to the illness that was commonly reported by caregivers:

1) accompanying the patient to hospital visits,
2) supervising the patient's medication use,
3) listening to the patient, and
4) "dophou" (keeping watch).

It also seems that the low functioning patient introduces a greater burden when compared to the high functioning patient in this domain. Caregivers felt that low functioning patients lack various abilities of everyday functioning, thus relatives may have been unable to act without the assistance of the caregiver. This lack of independence by low functioning patients, however, posed greater demands for the carer compared to high functioning relatives.

Due to the toll that schizophrenia may have on a person's psychological and social functioning (Asmal et al., 2014; Esan et al., 2012), and the partial or entire loss of these skills in some cases, the majority of participants had to accompany their relative to multiple hospital visits. This in turn, led to disruption of caregivers' usual routines, and also may have

put physical strain on older caregivers. As it will become clear later in this section, at healthcare institutions caregivers experienced numerous other challenges.

It was also the case that caregivers frequently had to supervise the patient's antipsychotic medication use. Caregivers had realised the constructive changes that medication adherence introduced to their relatives' lives (Saunders & Byrne, 2002). However, caregivers voiced that the difficult patient had diminished insight about their schizophrenia (Motlana et al., 2004), and as a result opposed treatment; consequently, the side-effects of treatment and patients' lack of insight led to poor adherence. Some may argue that to reduce this burden, the more appropriate choice may be to administer antipsychotic medication through depot injections (e.g., Haloperidol, Risperidone, or Zuclopenthixol) which are usually administered every two to four weeks (depending on patient factors and the dose of the antipsychotic). It should be noted that my study failed to, specifically, enquire about the treatment regimes that were followed by patients, and thus one cannot determine if all patients were on oral or depot antipsychotic treatment plans. According to Tiihonen et al. (2011), depot antipsychotic treatment is the treatment of choice for patients who display poor treatment compliance and have inadequate insight about their illness. However, caregivers like Doris challenged the effectiveness of depot antipsychotics that are used for a prolonged period. Caregivers also experienced that substance misuse or abuse can diminish antipsychotics' efficacy. While Doris' case may be an exception, further research in this domain can increase our understanding about the factors that influence the effectiveness of prolonged depot antipsychotic regimes.

Throughout caregiving or during difficult times, caregivers also needed to be actively present, listening to the needs of their relative (Kate et al., 2014). One of the most pervasive burdens for caregivers was the act of being vigilant – or what they termed "dophou" (keeping watch). Caregivers could never disconnect from their caregiving responsibility. Caregivers needed to act when their relative experienced distressing moments caused by the schizophrenia. Moreover, caregivers were worried about their relative's actions or inactions; possibly caused by the negative symptoms of schizophrenia (e.g., forgetting to turn off the stove).

In summary, the caregivers continued with or intensified many activities of caregiving, and had to take on others in the context of the illness. This care work coincided, of course, with caregivers' getting older. It is therefore probably not surprising that participants were burdened with experiences of physical strain. In addition, caregivers'

normal sleep patterns were commonly disrupted by the patient or as a result of the carer's caregiving responsibilities. Subsequently, caregivers could not rest sufficiently.

Effects on social environment. As previously explored by Bauer et al. (2012), having the person with schizophrenia at home further introduced various burdens to the social environment at home. As early as the stage of diagnosis, caregivers experienced a depressing milieu at home. Additionally, not only did the patient's problematic behaviour (e.g., aggression or violence) create difficulties at home and in the community, there was, at times, caregiver-patient conflict and, at times the patient also clashed with others at home (Molefi & Swartz, 2011). What further complicates this is the fact that some caregivers also provided housing to younger children who, like the caregivers, also may have a limited understanding of schizophrenia and the consequences thereof. This may create a context for increased conflict.

Problematic behaviours and lack of social support. Many researchers have discussed problematic behaviours that people with schizophrenia may display (Mhaule & Ntswane-Lebang, 2009; Molefi & Swartz, 2011; Negota & Mashegoane, 2012). In this study, caregivers voiced multiple accounts of patients' problematic behaviours. As found by Negota and Mashegoane (2012), aggressive and destructive behaviours were a common difficulty faced by many caregivers in my study. In addition, caregivers in my study offered accounts where the person with schizophrenia engaged in problematic behaviours prior to the onset of the disorder, possibly as part of the prodromal phase of the illness (e.g., while attending school).

The effects of the problematic behaviours on caregivers' psychological and social well-being was identified in the results sections. Caregivers experienced a range of emotions when their relatives displayed problematic behaviours – fear, frustration, helplessness, and worry. Moreover, by being preoccupied with the demands posed by the patient's problematic behaviours, caregivers, who already experienced a lack of social support, might have been forced to withdraw from social interaction even more. My data suggests that a lack of social support introduces an intense subjective burden for caregivers. Two symptoms of this burden were evident during the interviews as well. First, caregivers cried while voicing the lack of social support that they experienced; and second, caregivers used the term "dis swaar" (it is heavy) in their narratives during discussion. It should be noted that the chapter later discusses social support as a perceived coping mechanism.

Facing moments of distress. Another debilitating consequence of having to care for a person with schizophrenia is that caregivers get to witness the times when their relative

experiences distress caused by the symptoms of the disorder (Bauer et al., 2012). More than half of all caregivers reported that they endured moments where the patient experienced anxiety, depression, heartache, fear, or helplessness. These encounters were some of the hardest that caregivers had to face. This was confirmed by caregivers' emotionally loaded narratives. This further confirmed the findings by Gutiérrez-Maldonado et al. (2005) that mothers of children with schizophrenia commonly experience intense heartache when providing care. The possible emotional impact that these encounters have on the caregivers themselves has been introduced in Chapter Five and is discussed later in this chapter.

Dependency and disruption. Caregivers portrayed low functioning patients as individuals who lose their ability to act independently. Caregivers had realised this, and as a result took over or facilitated various roles, which would have been fulfilled competently by independent or high functioning patients. However, carers experienced this process as the patient becoming dependent on them. Thus, my findings are similar to that of Gutiérrez-Maldonado et al. (2005) who found that caregivers experienced a loss of their own independence as a result of care burden.

In many cases patients lacked the cognitive or social skills to act independently and carers had to act or supervise their relative's actions. My findings further offer a possible connection between caregivers' experiences of patient dependency and disruption of carers' lives. As recently explored by Iseselo et al. (2016), caregivers in my study experienced their lives as disrupted by their relative with schizophrenia. Iseselo and his colleagues (2016) highlighted disruptions occurring in the family's functioning and in household routines. Similarly, participants in my study experienced that caregiving disrupted their lives. For example, caregivers were disrupted in their sleep patterns and career responsibilities – it was commonly the problematic behaviours of relatives that led to the disruption. Because patients were unable to act independently, caregivers felt obligated to care for their relative, which disrupted their lives in various ways, as reported.

When caregivers' commitment to caregiving disrupts their career, this may result in financial burden for the family (Ohaeri, 2001; Thara et al., 2003). This is because many caregivers may also be the primary breadwinner for their families. However, while living in a state of poverty, few caregivers reported financial burden in my study. As a result, my findings differ from that of Ohaeri (2001) and Thara et al. (2003). A plausible explanation for lack of financial burden can be linked to the annual income of caregivers. Furthermore, the fact that many caregivers were married or in a relationship meant that caregivers could rely on financial assistance from their partner. It should however be noted that caregivers

like Charlie and Zelda voiced their experiences of financial burden that resulted from the patient's problematic and destructive behaviour (Martínez, Nadal, Beperet, & Mendióroz as cited in Gutiérrez-Maldonado et al., 2005).

Difficulties in interaction with healthcare resources. As described in Chapter One, South Africa experiences multiple challenges in providing healthcare, and resources are not sufficient for provision (HRW, 2011; Lund et al., 2010; Lund et al., 2012). In light of this, it could have been expected that caregivers would voice the repercussions of these difficulties in their interviews. As stated earlier, caregivers felt that, at times, healthcare providers were uninvested in their concerns and cases. There may be multiple reasons for this perceived lack of investment from healthcare professionals. South Africa has fewer people working in mental health and health in general than in wealthier countries, especially in the public sector (Collins et al., 2011), and healthcare professionals are overburdened with patient numbers (HRW, 2011).

Furthermore, caregivers stated that they had not received sufficient information about schizophrenia from general healthcare practitioners. It may also be the case that primary healthcare personnel may not have enough knowledge about schizophrenia to assess patients and intervene effectively (Collins et al., 2011; HRW, 2011; Lund et al., 2010; Lund et al., 2012). Caregivers in my study more than once voiced the importance of specialist healthcare workers (e.g., psychiatrists and psychologists) and the constructive value that these clinicians offer to schizophrenia treatment and caregiver coping. There were also some indications that caregivers found it difficult to access specialised mental healthcare resources in the community. Lastly, it was interesting to hear that schizophrenia is frequently misdiagnosed by doctors. Issues of what participants experienced as lack of competence on the part of primary care personnel and misdiagnosis of schizophrenia were experienced as particularly distressing. It must be borne in mind, though, that regardless of the competence of clinicians, early diagnosis of schizophrenia may be difficult. Many early and prodromal features of the illness are commonly associated with other physical and mental disorders (APA, 2013). As a result, healthcare clinicians, and primary healthcare personnel in particular, have to sift through a wide range of symptoms to form an appropriate diagnosis. This may not always be an easy task for clinicians, considering the context of our healthcare service delivery in South Africa. Misdiagnosis of schizophrenia, especially in its early stages, is a common experience that burdens caregivers, and is affected by lack of resources and skills, and further exacerbated by the real challenge of differential diagnosis and treating patients' co-morbid complications (e.g., substance abuse or other physical illness).

Experiences of Subjective Burden

The caregivers reported experiences of subjective burden in multiple domains of their everyday lives. As stated in Chapter Five, caregivers had experienced a wide range of emotions since their relative's diagnosis, and while providing care for the person with schizophrenia. Experiences of subjective burden were encapsulated by at least four themes or sub-themes in Chapter Five. These themes include:

1) illness related behaviours;
2) patient abused by community members;
3) emotional impact on caregiver; and
4) living with a sense of obligation to care.

According to the definition of experiences of subjective burden, it is the caregiver's emotional reactions that are a response to the experiences of objective burden; it may appear that *illness related behaviours* and *patient abused by community members* do not fit in this section. However, I found it appropriate to include these two themes in this section, as experiences that they represent commonly evoked emotional reactions from participants in my study.

Illness related behaviours and patient abuse. My findings suggest that the illness related behaviours and the distressing moments, which patients had to endure while living with schizophrenia, burdened caregivers emotionally. When caregivers had witnessed the illness related behaviours in, or the abuse that community members inflicted on their relative, emotional responses followed. Participants commonly experienced emotional reactions of fear, heartache, and uncertainty. This can be attributed to caregivers' empathy towards their relative; or to caregivers' synchronisation with the patient's emotional state. As one caregiver put it: *"ek meen dit raak mos nou jou body language" ("but I mean that becomes your body language")*.

Emotional impact on caregiver. A body of literature has explored the emotional experiences of caregivers of people with schizophrenia (Mhaule & Ntswane-Lebang, 2009; Negota & Mashegoane, 2012; Saunders & Byrne, 2002). The theoretical framework that was utilised in my study allowed me to further explore caregivers' emotional experiences in particular. Many emotional reactions, such as distress, frustration, guilt, sadness, stigma, and worry, overlap with local findings by Mhaule and Ntswane-Lebang (2009). Other emotions,

such as heartache, helplessness, and uncertainty, are in accordance with the work of Saunders and Byrne (2002). My findings suggest that caregivers react emotionally at two distinct stages – first, upon the diagnosis of their relative (Negota & Mashegoane, 2012), and thereafter, throughout the course of being caregiver.

At the stage of diagnosis. Negota and Mashegoane (2012) found that during the phase that the disorder is first diagnosed, caregivers experienced anger, fear and frustration; possibly due to their lack of knowledge on how to handle the situation. However, my findings have slightly different implications. At the stage of diagnosis, participants experienced disappointment, heartache, and shock. Their disappointment resulted from the fact that they had hopes and ideals for their children, and at that stage these were diminished by the diagnosis (Negota & Mashegoane, 2012). Participants expressed heartache because they felt helpless in the situation; others felt heartache, as more than one of their children was now living with schizophrenia. Lastly, at least five participants experienced a sense of shock when their relative was diagnosed. This suggests that, while some individuals suspected the schizophrenia, most caregivers had not expected the diagnosis at the time. Participants also felt that the patient will have little to no chance of continuing a "normal" life whilst living with schizophrenia. While this falls outside the scope of my research, a body of literature exists on the topic of recovery in schizophrenia and increasing the quality of life in persons with schizophrenia that may serve to alleviate caregivers from emotional burdens in this period (Bellack, 2006; De Wet et al., 2015; Jacobson & Greeneley, 2001; Liberman & Kopelowicz, 2005).

The long-term emotional experience of caregiving. Throughout caregiving numerous emotional experiences burdened caregivers:

1) feeling ashamed,
2) disappointed;
3) a sense that life had become "swaar" (difficult);
4) fear;
5) frustration;
6) guilt;
7) heartache;
8) a sense of helplessness;
9) experiences of loss;
10) feeling stigmatised;
11) feelings of distress;

12) uncertainty; and

13) worry.

While each of the 13 emotional reactions stated in Chapter Five would have represented caregivers' realities, five emotions stood out about the rest. This, however, does not imply that we should ignore the other eight emotional experiences, as they indisputably exacerbate caregivers' emotional burden load.

In general, participants, and some deeply, felt being a caregiver and caregiving as a difficult task (Mhaule & Ntswane-Lebang, 2009). It appeared as if factors such as the accumulation of caregivers' life stressors, and the debilitating consequences of schizophrenia, introduced challenging experiences for caregivers. Additionally, caregivers frequently experienced a sense of frustration throughout caregiving. Molefi and Swartz (2011) had previously explored reasons for caregivers' experiences of frustration. My results, however, provide limited exploration of this emotion among participants in my study. As Negota and Mashegoane (2012) found, caregivers in my study also voiced the sense of loss that they experienced. My findings attribute this sense of loss to two factors. First, caregivers felt that they had lost the person they knew before the patient became ill. Second, caregivers had ideals and hope for the patient, and these were lost after the patient became ill. If one considers the characteristics that caregivers note in the low functioning patient, loss can be viewed as a pervasive experience that accompanies caregivers' encounter with schizophrenia.

Stigma was something that caregivers could not escape, as stigmatisation had its roots in close proximity to the caregiving environment (e.g., family) and also by members of the community. One may argue that not only caregivers, but also society, lack knowledge about schizophrenia and therefore tend to stigmatise odd behaviours that are displayed by people with schizophrenia. A number of studies have reported caregivers' accounts of feeling stigmatised (Koschorke et al., 2014; Kung, 2003; Magana et al., 2007; Von Kardorff et al., 2015). Kung (2003) stated that stigma directly increases caregivers' experiences of subjective burden. Additionally, perceived stigma can also be linked with symptoms of mental disorders (e.g., depression) in caregivers (Magana et al., 2007). The increase in subjective burden can be attributed to the reason that stigma causes caregivers to withdraw from social support resources (e.g., interactions with friends and family, or accessing personal healthcare resources). Caregivers, therefore, became socially isolated, confined to their homes. In turn, social isolation intensified caregivers' experiences of objective burdens (Kung, 2003).

Yet, it appears that little progress has been made to create public awareness regarding schizophrenia in Africa. My study confirms this and suggests that serious action needs to be taken to create awareness about schizophrenia. This may ultimately contribute to reducing this burden for caregivers in the future.

Guilt, and obligation to care. The last emotion that my study reported on was caregivers' feelings of guilt. Caregivers felt that it was their fault that their relative became ill and blamed themselves for this. Moreover, caregivers may have experienced shame because of their relative's odd behaviour and others reactions to it. Some may argue that caregivers felt that, like the patients, they were being "dopgehou" (watched) by others in the community. As a result, many caregivers experienced a sense of obligation to care for their relative with schizophrenia. It was the caregiver's obligation to intervene, to treat the patient's odd behaviours out of the eye of the public.

All but two caregivers reported their sense of obligation to provide care for their relative. My findings suggest that mothers could not bear their children's moments of distress or the characteristics of loss that patients displayed; and therefore acted to enhance the patient's quality of life. Also, in most cases the patient was the child of the caregiver and caregivers felt that they could not burden others with the responsibility of caring for them (Iseselo et al., 2016). Lastly, caregivers also felt that it was God's will that their child had schizophrenia and subsequently it was the carer's duty to care for the patient.

Against this backdrop, psychoeducational interventions, such as that of Asmal et al. (2014), can inform caregivers about various caregiver-unrelated factors (e.g., substance abuse by; or traumatic experiences of, the patient prior to the onset of schizophrenia) that contribute to the onset of the disorder (Burns, Jhazbhay, Esterhuizen, & Emsley, 2011; Cannon et al., 2008; D'Souza et al., 2005; Hambrecht & Häfner, 1996; Kristensen & Cadenhead, 2007; Morrison et al., 2009; Seedat et al., 2003). Thereafter, caregivers' experience of guilt may lessen. I specifically refer to Doris' case where she reported experiencing relief when she had realised that schizophrenia is a heritable illness and not a punishment for sins that she had committed.

Caregivers did indeed report that many patients experienced both substance abuse and traumatic experiences prior to the onset of their psychosis. However, one cannot claim that it was indeed these factors that caused the schizophrenia in the patients who were being cared for by caregivers in my study. Therefore, it is worth exploring persons with schizophrenia's experiences of substance abuse and trauma in future research. Interestingly, however, Seedat et al. (2003) argue that up to 98% of individuals with severe mental disorders have reported

at least one trauma experience prior to the onset of schizophrenia. Alternatively, Seedat et al. (2003) also note, patients further experience trauma while living with schizophrenia. The symptoms of schizophrenia and various schizophrenia treatment strategies (e.g., hospitalisation) can be traumatic experiences for the patient.

Furthermore, psychoeducation can assist caregivers in becoming aware that it is not necessarily always their obligation to care for their relative – there may be various schizophrenia-care institutions in the community that can provide specialised care to patients. Many of these institutions are out-patient orientated (e.g., Stikland Psychiatric Hospital), in that they accommodate patients during the day, and allow them to go home in the afternoon. Ultimately, when caregivers come to these insights and are empowered with this knowledge, they may experience less shame and guilt, or obligation to care.

Caregiver Coping

Caregivers' coping strategies were conceptualised through the Transactional Model of Stress and Coping framework (Folkman & Lazarus, 1988). As discussed in Chapter Two, caregivers can utilise emotion-focused and/or problem-focused coping mechanisms. It is possible that caregivers can, at times, cope by utilising a combination of these two mechanisms (Folkman & Lazarus, 1988); but, this section discusses the different coping strategies independently. It should be noted that my study did not aim to investigate the effectiveness of either emotion or problem-focused coping mechanisms; yet, my findings may form the foundations for future research on the effectiveness of coping mechanisms in caregivers of people with schizophrenia.

However, before I do so, my study also found various coping strategies, which per definition may not fit into either emotion or problem-focused techniques. Possible reasons for this is that the coping mechanism was present before the onset of the relative's schizophrenia; or that the individual did not specifically act – physically or emotionally in response to the situation, created by their caregiving responsibility, to alleviate their perceived stress. As these mechanisms emerged under the *Qualities of the caregiver* theme family in Chapter Five, I discuss them accordingly.

Qualities of the Caregiver

Having a life partner. At least five caregivers reported that having a life partner facilitated their sense of coping with stressful situations. By having a life partner, caregivers felt that they did not have to face challenges alone. Support received from one's life partner can impact the outcomes of coping, but also alleviates the caregiving burden of "being the only caregiver". My findings suggest that sole caregivers struggle with the demands that general life and schizophrenia caregiving introduced. Furthermore, having a life partner can also serve as one of the first forms of social support coping mechanisms that decrease caregivers' burden of sense of being isolated and lack of social support.

Religion and coping. Religion can be classified as an emotion-focused coping strategy. I chose to exclude it from the emotion-focused section, specifically because caregivers were religious prior to the onset of their relative's schizophrenia – but relied on it throughout the caregiving role. In her thesis, De Wet (2013) states that

> Spirituality [religion] is a theme that is often avoided, perhaps because spirituality [religion] is a topic that is often shrouded in controversy and regarding which many wide-ranging opinions exist. To overlook spirituality [religion] in this discussion, however, would be tantamount to silencing a crucial part of the voice of some of the participants (p. 91).

This was also the case in my study. The majority of caregivers reported that their religion (being religious; or engaging in and accepting of religious acts) facilitated their coping with difficult times. Therefore, excluding religion in discussion would deny a key aspect of caregivers coping experiences.

According to Rammohan et al. (2002), strength in religious belief is an important coping mechanism for caregivers of people with schizophrenia and has been linked with enhanced well-being. Moreover, religion appears to be an effective coping strategy for patients with schizophrenia and other mental disorders as well (De Wet et al., 2015; Kroll & Sheehan, 1989). Especially in the context of older women who live in economically disadvantaged conditions and with limited social support and financial resources, like the caregivers in my study, religious coping serves as solace for caregivers in situations that they have little control over (Huang et al., 2008; Rammohan et al., 2002). Therefore, it may be the case that when caregivers together with their relative, engage in religious acts at home, the whole family's coping may be enhanced. However, further studies on the interaction of

caregiver and patient religious coping may inform us about its effectiveness in the context of schizophrenia and in Africa.

Emotion-focused Coping Strategies

As stated earlier, in emotion-focused coping, individuals aim to regulate their stressful emotions. As a result, the person can experience a range of emotions that alter the meaning of their situation, and reduce their perceived sense of stress (Folkman, 1984; Folkman & Lazarus, 1988). Several researchers have reported that emotion-focused coping strategies induce high levels of caregiver burden (Magliano et al. as cited in Huang et al., 2008; Scazufca & Kruipers, as cited in Huang, et al., 2008; Solomon & Draine as cited in Huang et al., 2008). Therefore, while caregivers reported emotion-focused coping mechanisms, its effectiveness to decreasing perceived stress in caregivers, especially in the long run, is questioned. However, Nehra, Chakrabarti, Kulhara, and Sharma (2005) state that emotion-focused coping strategies are more common in caregivers of people with schizophrenia, compared to other mental disorders.

Aspects of emotion-focused coping were identified in at least five themes and their sub-themes in the results chapter:

1. fostering the positives;
2. acceptance;
3. avoidance;
4. downplaying the impact of caregiving; and
5. “we got strength to carry on”.

Positive thinking and coping. Caregivers in my study reported various methods of positive thinking (Caprara & Steca, 2005). According to Huang et al. (2008), positive thinking helps to reduce caregiver burden in schizophrenia. A possible reason for this reduction in perceived burden may be because of positive thinking’s effect on the psychological well-being of the individual. According to Caprara and Steca (2005), positive thinking strategies are highly correlated with one’s sense of life satisfaction, optimism, and increased self-esteem. It may also be the case that their positive thinking led to caregivers’ increased sense of life satisfaction, optimism and self-esteem when facing challenging times introduced by schizophrenia caregiving. McCann et al. (2009) state that caregivers commonly reflect positively on the interactions with patients with a mental illness – for

example, carers realise that their relationship with the patient has changed or increased in closeness. Similarly, my findings suggest that caregivers displayed love towards their relative, reflected with a sense of pride, and noticed recovery in the patient.

Moreover, though, my findings also suggest that caregivers' positive thinking can be directed inward – for example, caregivers' sense of confidence in caregiving, and hope for their relative's recovery (McCann et al., 2009). In its turn, inward positive thinking can foster resilience in caregivers, which can specifically reduce caregiving burden and enhance coping in the future (Caprara & Steca, 2005; McCann et al., 2009; Zauszniewski, Bekhet, & Suresky, 2009).

Caregivers had realistic expectations about their relative's behaviour and the outcomes thereof. Caregivers noted that impairments caused by the schizophrenia commonly led to the patient's loss of ability to master various tasks of everyday living (e.g., completing schooling; maintaining personal hygiene; or the forming of intimate relationships). As a result, many caregivers may have reacted with disappointment. However, Kung (2003) states that caregivers with lower expectations of patients' performance, experience a lower sense of disappointment; in this way carers may be able to cope with the let-downs caused by schizophrenia more effectively.

Many caregivers reported personal growth while being a caregiver (Ryff cited in Leipold et al., 2008; Hogan & Schmidt, 2002). This suggests that, despite the challenges that caregivers faced, they had developed resilience and matured emotionally, as a result of their experiences. Caregivers became more relaxed about their situation, and connected emotionally with others who faced similar challenges. Interestingly, my analysis showed that caregivers who had portrayed their relative as mostly being an easy patient were more likely to report personal growth. Furthermore, my findings suggest that acceptance as cognitive-emotional process facilitated caregivers' personal growth experiences.

Acceptance as coping mechanism. As stated earlier, emotion-focused coping mechanisms tend to be associated with high levels of caregiver burden (Huang et al., 2008). However, five caregivers explained that they had accepted their status quo and this facilitated their coping. For many caregivers, accepting their relative's diagnosis, enhanced carer-well-being, as their experiences of, particularly, guilt was relieved. Some may argue that caregivers might have been in denial or have illusions about their experiences. But, as acceptance is a cognitive-emotional process, so is the process of non-acceptance. A number of studies have reported that when individuals are not able to accept their relative's illness, caregiver burden increases (Anderson, Reiss, & Hogarty, 1987; Huang, Lee, & Mao, 1991;

Huang et al., 2008). According to Huang et al. (2008), caregivers' positive thinking creates the foundation for acceptance. When caregivers reach a point where they are able to accept their circumstances, the chances increase for caregivers to engage in problem-focused coping strategies.

Coping by avoiding conflict, and downplaying the impact of caregiving. Avoidance was a coping strategy that was used by most caregivers. Caregivers commonly chose to avoid interactions, which had the potential to ignite conflict, with their relative. Hassan et al. (2011) and Dyck et al. (1999) found that caregivers who avoid confronting challenging experiences experience more caregiver burden. A plausible explanation for this may be that when caregivers avoid, instead of act on, for example patient problematic behaviour, the problematic burden causing behaviour is not resolved or alleviated. Consequently, caregivers may suppress emotions like frustration or helplessness and increase their sense of subjective burden.

Furthermore, downplaying the impact of caregiving can also be interpreted as a form of avoidant behaviour – caregivers avoid facing the reality of the impact that caring for their relative has on their lives. Caregivers downplayed their relative's problematic behaviours at home, the demands of caregiving, and the negative effect that caregiving had on the carer's health. It is not uncommon for family members of people with severe mental disorders to experience compromised health, due to the burdens that they face (Saunders, 2003; Walton-Moss, Gerson, & Rose, 2005). Caregivers' health was also comprised after becoming a caregiver; however, caregivers downplayed this – I specifically refer to Doris' account. Different reasons may exist for this downplaying of caregivers' vulnerability, but it might be the case that caregivers already experience a sense of weakness or imperfection for having a child who is ill, and therefore caregivers themselves battle to confront their own frailty.

"We got strength to carry on". Similar to the findings of Shibre et al. (2003), caregivers in my study reported relying on their emotional strength. A plausible reason for caregivers' reliance on their own strength can be attributed to the lack of social support that they had experienced (Shibre et al., 2003). Alternatively, my findings suggest that caregivers' resilience, developed from challenging times in the past, contributed to their strength endurance. Caregivers who are strong may experience that they are coping effectively with the life-challenge, but, as a result, they do not engage in behaviours to alleviate the burdens that they face. Consequently, this prolonged state of stress may take its toll on caregivers and the symptoms thereof may surface in caregivers' emotional (e.g.,

frustration, helplessness, uncertainty); psychological (e.g., anxiety or depression); and physical (e.g., energy depletion) behaviours.

Problem-focused Coping Strategies

As stated earlier, in problem-focused coping, individuals act on an environmental stressor in an attempt to reduce the stress associated with it (Folkman, 1984; Folkman & Lazarus, 1988). As my findings indicate, caregivers can act, or withdraw from acting, or accept actions from others in their environment to facilitate problem-focused coping techniques. Aspects of problem-focused coping were identified in at least 12 themes and their sub-themes in the results chapter:

1. making sense of the schizophrenia;
2. self-education on schizophrenia;
3. not challenging lack of insight;
4. not shouting at the patient;
5. anticipating the patient's needs in advance;
6. living in the moment;
7. being vigilant;
8. investing in their own needs;
9. professional healthcare services;
10. lay-care services;
11. police services; and
12. social support.

Making sense of the schizophrenia and self-education. Caregivers' lack of knowledge about schizophrenia was a day-to-day challenge. Caregivers' lack of knowledge may be regarded as exacerbating other challenges that are experienced – especially in terms of emotional experiences of uncertainty and guilt. However, caregivers appeared motivated to overcome this difficulty. In order to do so, caregivers made sense of a range of experiences related to schizophrenia and caregiving. For many caregivers, their attempts to understand the factors that led to the onset of their relative's schizophrenia facilitated their coping. Furthermore, caregivers like Betty realised that antipsychotic medication enhances the patient's recovery. My findings further suggest that for many caregivers, relying on their own to make sense of the schizophrenia was not enough. Similar to caregivers in the Huang

et al. (2008) study, caregivers engaged in activities to increase their knowledge about the disorder (e.g., reading books on schizophrenia). Caregivers in my study experienced a sense of empowerment when they understood their situation better.

Caregivers' knowledge of schizophrenia and about what to expect from their relative influenced the way in which carers approached interactions with the patient. It is also possible that emotion-focused coping strategies, like avoidance, may have affected the interaction pattern between caregivers and the patient. Nevertheless, caregivers seemed to be aware of the lack of insight that, particularly, difficult low functioning patients had about their illness. Consequently, while being frustrated at times, caregivers chose not to physically display their frustrations when in conflict with their relative with schizophrenia. For example, caregivers did not shout at their relative, since they had also learned from past experiences that shouting at the patient caused distress, and may hinder recovery.

Being vigilant, living in the moment, and anticipating the patient's needs in advance. Caregivers were aware that if they had not been vigilant about their relative's whereabouts, stressors would increase in the caregiving environment. They felt the need to keep a watchful eye on the patient, but at the same time this act allowed them to live in the moment of their experiences. In the moment, various emotion or problem-focused coping mechanisms may function in combination to assist caregivers through the difficult times. One example of living in the moment is when caregivers synchronise their behaviour with that of the patient.

Caregivers realised that the impairments caused by schizophrenia limit their relative's abilities to execute daily tasks, and also that the patient's behaviour may unintentionally cause dangers at home. As intervention, caregivers attended to patient's needs in advance. Thereafter, caregivers' levels of worry were reduced for the moment. One example where caregivers attended to their relative's need in advance is when carers prepare the patient's antipsychotic medication in advance, and, thereafter gives it to the patient to take. While, this additional activity introduced by caregiving may also serve as an objective burden to caregivers, my findings suggest that caregivers had realised that in order to enhance their coping, certain burdens need to be endured.

Investing in their own needs. Caregiving, undeniably, took its toll physically, psychologically, and socially on caregivers. It may also be the case that older caregivers were burdened with health complications that accompany aging. My findings portray caregivers as people who continually act to integrate two overlapping aspects of their life: 1) their personal life and events not related to caregiving, and 2) their roles and responsibilities

as being a caregiver. One should note that some caregivers could, however, not disconnect from either life domain; and it seemed that caregivers found this integration difficult. As coping mechanism, apart from attending the demands of their relative, caregivers took responsibility to invest in their personal needs as well. Caregivers in my study invested, mainly, in three needs. First, caregivers invested in their personal health. Second, caregivers engaged in recreational activities for enjoyment. Third, caregivers also realised the need for independence. By attending to their own needs, and integrating this with caregiving responsibilities, caregivers were able to cope with the burdens that schizophrenia caregiving introduced.

Professional healthcare, police services, and lay-care. Away from home, caregivers reported healthcare, police services, and lay-care as coping resources. Despite the challenges that caregivers experienced at healthcare services, the majority of carers valued the assistance from clinicians. Their appreciation can be attributed to the fact that, at healthcare facilities, clinicians provided specialised treatment to themselves and their relative. Caregivers voiced the effectiveness of specialised mental healthcare and how clinicians in this domain approached the patient more suitably for treating their schizophrenia. Moreover, police services were utilised to assist caregivers during times when their relative displayed problematic behaviours. Caregivers feared the consequences of confronting the patient when they were aggressive or destructive. Lastly, some caregivers reported that lay-care assistance from other family members facilitated their coping with the demands of caregiving. It may be the case that when caregivers can rely on another carer, that the primary caregiver is able to disconnect from their role as caregiver. However, the minority of participants in my study had realised the value of having lay-care assistance.

Social support. "Social support usually comes from friends and family and being able to call on these resources is one of the most important aspects of coping" (Huang et al., 2008, p. 823). Consequently, and as my findings suggest, the lack of social support lies at the heart of many caregivers' burden – carers battle to fulfil the caregiving role alone. During difficult times, caregivers needed support from other to help them cope or alleviate burden. Here, caregivers' family and friends are key sources of social support, as interactions with them serves to alleviate stressors that carers experience. My study found that caregivers' social support is mostly limited to individuals that are in close proximity to the caregiving environment (e.g., family and friends that have frequent interactions with the caregiver). One may argue that, ideally, caregivers' social support resources should extend to community or organisational level as well. Besides from receiving psychoeducation during consultations

with healthcare clinicians, caregivers experienced limited support from resources away from home. Support groups with other schizophrenia caregivers may provide suitable intervention here.

Abroad, a body of literature has investigated the effects of support groups on caregivers' coping ability, and improved well-being (Chien & Thompson, 2013; Yesufu-Udechuku et al., 2015). Both, Chien and Thompson (2013), and Yesufu-Udechuku et al.'s (2015) systematic review suggest that peer-led social support groups are an effective intervention for caregivers of people with schizophrenia when it is long-term orientated. Additionally, when caregivers, together with their relative with schizophrenia attend support groups both parties' quality of life improves (Chien & Chan, 2013; Chien & Thompson, 2013; Yesufu-Udechuku et al., 2015). First, the family functioning improves; second, recovery is enhanced in patients. Participants in my study offered no accounts of caregiver support groups, and therefore, could not report it as a recovery enabling factor when describing the patient. Yet, in Africa research investigating the effectiveness and feasibility of support groups for schizophrenia caregivers is limited. Asmal et al. (2014), however, found that family support groups with psychoeducation and behaviour modification components are effective in enhancing caregivers' and patients' mental health, and feasible in the local socio-economic context. Research such as that of Asmal et al. (2014) is limited, and therefore the need exists for future research in the schizophrenia-caregiver support group domain.

Strengths and Limitations, and Recommendations

In this section, I discuss the strengths and limitations of my study and how it may have impacted the outcomes of the project. I also offer recommendations for future researchers.

Strengths and Limitations

This section first describes the strengths to my study. Thereafter, the limitations to my work are discussed.

The first strength of my study was that my study was one of only two of its kind in the context of the Western Cape and South Africa. The Molefi and Swartz (2011) study was conducted in a similar context as my work and their research did explore family members' "experience of living with a relative with schizophrenia" (p. 239), however, their participant

sample differed from mine. Additionally, my study adds to the small body of work available on caregivers' experiences of caring for a person with schizophrenia.

The second strength exists in the fact that my study explored the caregivers' subjective experiences of challenges and coping mechanisms, thus my findings may be used to form the basis for intervention studies for these individuals (Joubert, 2014). In considering the emotional accounts of many participants, it is my hope that future studies will emerge from this new literature that specifically focus on bio-psycho-social interventions for schizophrenia caregiver burden.

Third, my study's qualitative nature enabled me to meet face to face with research participants, and as a result I was able to discuss my research topic with them in depth. At the same time this interaction fostered a relationship between me and the caregivers. The strength of such an interactive relationship is that the investigator obtains a firsthand experience of the phenomenon being studied (Carr, 1994). As the duration of interviews became longer, the validity and honesty of caregivers' stories were likely to increase. Consequently, I obtained a "genuine understanding of the dilemma faced by participants of sick or handicapped children" (Carr, 1994, p. 718).

The first limitation to my work is that my study was qualitative and exploratory in nature, thus it investigated few cases, and as a result, it is not possible to make generalisation from my findings. However, Lincoln and Guba (1985) argue that it is not the goal to generalise findings from qualitative studies. Therefore, my study served to fill a gap in existing schizophrenia caregiving literature in Africa. Additionally, my study can serve as a methodological triangulation strategy (VandenBos & APA, 2015) for the quantitative work that is being conducted on caregivers in the Shared Roots Project. Furthermore, information was generated from a homogenous sample of caregivers – particularly with regards to age, gender, and socio-economical background. As a result, my findings may not be a representation of caregivers' who characterise different traits.

The second limitation to my work is that my study was cross-sectional in nature. The information, which I reported on in this thesis, was collected from caregivers at one point in time and not through multiple interviews in longitudinal fashion (Bless et al., 2013). Therefore, one cannot conclude that all caregivers' experiences are accurate accounts of the holistic caregiving experience. Properties of the caregiver that are unknown to me and out of my control may have influenced carers to share the specific content they had shared on the day of the interviews. It may be the case that if my study had been longitudinal in nature these caregiver-characteristics could have been identified and integrated into the caregiving

experience. Then only, a more accurate reflection of the holistic caregiving experience could have been obtained.

The third limitation to my work is that I was the sole investigator in this project. Consequently, I guided interviews, interpreted narratives, and derived the findings myself. It is possible that my vulnerabilities, past experiences, and predispositions about schizophrenia and its caregiving may have steered the findings in the direction it did. I could have intervened by introducing investigator triangulation (VandenBos & APA, 2015) in my methodology. However, in response, I have disclosed a range personal factors that may have shaped the outcomes of this study. I have also implemented a range of techniques to increase the trustworthiness of my study.

Recommendations

Based on the findings of my study, caregiver burdens and coping mechanisms were identified and explored. However, it would be beneficial to quantitatively investigate the affects of the caregiver burden and the effectiveness of the coping strategies that caregivers reported in my study.

As my work explored the experiences of a small and homogenous group of caregivers, it would be beneficial to investigate the caregiving experience of individuals from different sociodemographic backgrounds (e.g., different ethnicity, age, and socioeconomic status).

Conclusion

This study highlighted the subjective experiences of caregivers of deinstitutionalised individuals with schizophrenia in the Western Cape, South Africa. A relatively small and homogenous sample of 13 caregivers participated in my study, yet their accounts provided us with a deeper insight into the realities of caregivers of people with schizophrenia.

Throughout this thesis, it became clear that schizophrenia is a complex and debilitating mental disorder that introduces a wide range of challenges to the patient, but also to their caregivers. Some challenges arise even before the formal onset of the disorder, whereas others are introduced on, or after the patient's diagnosis and continue to burden caregivers throughout their caregiving experiences. This thesis has illustrated that caregivers feel that some challenges are in fact introduced by having the patient live at home and the

consequences thereof. However, caregivers reported that they are additionally burdened with other contextual difficulties that may be created by themselves, other family members, their friends, or members of the community.

This thesis has further explored caregivers' coping strategies which they utilised to overcome challenges introduced by their relative with schizophrenia. Caregivers develop or equip themselves with coping strategies to handle the immediate, and sometimes unexpected, challenges that occur during caregiving. It has also illustrated that caregivers equip themselves with long-term orientated coping strategies that may carry them through periods of difficulty. Emphasis was given to the role that others (e.g., family members or healthcare professionals) can play to facilitate the well-being of the patient and their caregivers. Lastly, some caregivers also reported positive, character building experiences arising from their caring for their relative with schizophrenia.

Being a caregiver of a person with schizophrenia ultimately changes the course of caregivers' lives completely. Each caregiver voiced unique experiences of their lives and living as caregiver, and while there may be an overlap in caregivers' experiences of caregiver burden and coping, no two participants reacted towards becoming a caregiver in the same way. We should bear in mind that caregivers also have other roles to play in society and that being a caregiver for a relative with schizophrenia is one aspect of caregivers' multidimensional lives.

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APPENDICES

Appendix A

Interview Schedule

English Interview Schedule: Questions for participants

1. Please tell me about yourself and your family.
2. What do you call the condition that your family member has?
3. How long have they been living with this condition?
4. Where does he/she stay? How often do you interact with your family member with schizophrenia (for the rest of the interview, refer to *schizophrenia* in the term they coined it at *question 2*)?
5. How did you feel at the time of their first diagnosis with schizophrenia? (probe for emotional effects/reactions)
6. Please tell me about your experiences of caring for an individual with schizophrenia.
7. How does the caring responsibility affect your life? (give participants opportunity to answer this question first, before proceeding to 7 a, b, c, etc.)
    a) How does caring for a person with schizophrenia affect your relationship with your other family members? (ask participants to explain an effect in relation to each family member in their house)
    b) How does your caring responsibility affect your relationship with your friends?
    c) How does the caring responsibility affect your work (job)?
8. In what other ways has your life changed after your family member's diagnosis?
    a) How has your life changed for the better?
    b) What has made your life more difficult or unpleasant?
9. Will you please tell me about the challenges you experience from caring for your family member? (probe for: intrapersonal, interpersonal, and environmental challenges)
    a) What makes it difficult for you to care for your family member?
    b) How does your family member with schizophrenia make it difficult for you to care for him/her?
    c) What challenges does the outside-world introduce that make it difficult for you to care for your family member?
    d) Are there any other challenges that you experience and want to tell me about?

10. What helps you to cope with the caring responsibilities? (give participants opportunity to answer this question first, before proceeding to 10 a, b, c, etc.); (probe for personal properties, social support, professional resources)
    a) What strategy do you take to provide care for your family member?
    b) What are some of your strengths that help you to cope with the caregiving responsibility?
    c) How do your other family members help you to cope with the caregiving responsibilities?
    d) How do your friends help you to cope with the caregiving responsibility?
    e) Do you receive support from others in your community/neighborhood? What types of support?
    f) What has the healthcare system done for you and your family member with schizophrenia? (probe for: caregiver treatments, treatment plans)
    g) Are there any other factors/strategies that help you to cope with the caregiving of your family member? Will you please tell me about them?

Afrikaanse Onderhoudskedule: Vrae aan deelnemers

1. Vertel asseblief vir my van jouself en jou gesin.
2. Wat noem jy die kondisie waaraan die lid van jou gesin ly?
3. Hoe lank leef die persoon in jou gesin al aan die kwaal?
4. Waar woon hy/sy? Hoe dikwels het jy interaksie met jou gesinslid wat skisofrenie het? (vir die res van die onderhoud verwys na *skisofrenie* vir die term wat die deelnemer in vraag 2 gebruik het).
5. Hoe het jy gevoel toe jou gesinslid vir die eerste keer gediagnoseer is met skisofrenie? (probeer hier om emosionele reaksies te bepaal).
6. Vertel asseblief vir my van jou ervarings terwyl jy ’n individu met skisofrenie versorg.
7. Hoe beïnvloed die versorging van ’n persoon met skisofrenie jou daaglikse lewe? (gee deelnemers eers die geleentheid om hierdie vraag te beantwoord voor voortgaan met vrae 7 a, b, c, ens.)
    a) Hoe beïnvloed die versorging van ’n persoon met skisofrenie jou verhouding met jou ander gesinslede? (versoek die deelnemer om te verduidelik hoe dit sy/haar verhouding met elke afsonderlike gesinslid beïnvloed.)
    b) Hoe beïnvloed die versorging van ’n persoon met skisofrenie jou verhouding met jou vriende?
    c) Hoe beïnvloed die versorging van ’n persoon met skisiofrenie jou werk?
8. Op watter ander maniere het jou lewe verander nadat jou gesinslid gediagnoseer is?
    a) Hoe het jou lewe ten goede verander?
    b) Wat het die lewe vir jou moeiliker of meer onaangenaam gemaak?
9. Vertel asseblief vir my van die uitdagings wat jy ervaar vandat jy die gesinslid met skisofrenie moet versorg. (Probeer hier om intrapersoonlike-, interpersoonlike- en omgewingsuitdagings te bepaal.)
    a) Wat maak dit vir jou moeilik om jou gesinslid te versorg?
    b) Op watter manier maak jou gesinslid dit vir jou moeilik om hom/haar te versorg?
    c) Watter uitdagings in die omgewing buite julle tuiste maak dit vir jou moeilik om jou gesinslid te versorg?
    d) Is daar enige ander uitdagings wat jy ervaar en wat jy graag aan my wil noem?
10. Wat help jou om die versorgingsverantwoordelikheid te hanteer? (gee deelnemers eers die geleentheid om hierdie vraag te beantwoord voor voortgaan met vrae 10 a, b, c, ens.) (probeer hier persoonlike eienskappe, sosiale ondersteuning en professionele hulpbronne bepaal.)

a) Watter strategie gebruik jy om jou gesinslid te versorg?
b) Wat is sommige van jou sterk punte/eienskappe wat jou help om jou versorgingsverantwoordelikheid na te kom?
c) Hoe help die ander gesinslede in jou gesin jou om jou versorgings-verantwoordelikheid te hanteer?
d) Op watter wyse help jou vriende jou om jou versorgingsverantwoordelikheid te hanteer?
e) Ontvang jy ondersteuning van ander mense in jou gemeenskap of woonbuurt? Watter soort ondersteuning ontvang jy van hulle?
f) Wat het die gesondheidstelsel vir jou en jou gesinslid wat met skisofrenie gediagnoseer is gedoen? (probeer hier inligting inwin met betrekking tot versorgers behandeling en behandelingsplanne.)
g) Is daar enige ander faktore/strategieë wat jou ondersteun in die versorging van jou gesinslid? Sal jy my asseblief meer van hulle vertel?

Appendix B

Participant Demographic Questionnaire

Name and Surname:_____

Pseudonym:_____

Please answer the following questions about yourself and your family:

Age:_____

Gender
(M/F):_____

Occupation:_____
_____

Marital/Relationship
status:_____

Ethnic group (racial
classification):_____

Estimate Annual
income:_____

How many people live with you (in your home) in
total:_____

How long have you, personally, been caring for your family member with schizophrenia?

_____
_____

How much time of your day is designated to caring for your family member with schizophrenia?

_____
_____

What is the gender (M/F) of family member that you care for?_____

What is the marital/relationship status of the family member that you care for?_____

Does your family member have an occupation? If yes, what does he/she do?

_____

_____

Deelnemer Demografiese Vraelys

Naam en van:_____

Skuilnaam:_____

Beantwoord asseblief die volgende vrae oor jouself en jou familie/gesin:

Ouderdom:_____

Geslag
(M/V):_____

Beroep:_____
_____

Huweliks-
/Verhoudingsstatus:_____

Etniese groep (rasse
klassifikasie):_____

Geskatte Jaarlikse
inkomste:_____

Hoeveel mense bly saam jou (in jou huis) in
total:_____

Hoe lank versorg jy al, persoonlik, vir jou familie-lid met skisofrenie?

_____
_____

Hoeveel van jou tyd word daagliks uitgesit aan die versorging van jou familie-lid met skisofrenie?

_____
_____

Wat is jou familie-lid met skisofrenie se geslag (M/V)?_____

Wat is jou familie-lid wie jy versorg se huweliks-/verhoudingsstatus?_____

Het jou familie-lid ‘n werk? Indien ja, wat doen hy/sy?

_____

_____

Appendix C

Consent Forms

English Consent Forms

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR SESSION 1

TITLE OF THE STUDY: Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa

REFERENCE NUMBER: S16/07/130

PRINCIPAL INVESTIGATOR OF STUDY: Divan Rall (under the supervision of Professor Leslie Swartz)

ADDRESS: Wilcocks Building, Stellenbosch University, Stellenbosch

CONTACT NUMBER:

Tel: 021 808 3446 (Department of Psychology at Stellenbosch University)

Tel: 021 938 9207 (Health Research Ethics Committee at Stellenbosch University)

Tel: 021 910 3605 (Stikland study unit)

You are being invited to take part in a research project about the experiences of someone caring for a family member living with schizophrenia.

Please take some time to read the information presented here, which will explain the details of this study. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this study all about and why is it important?

Although, some research has been done on the experiences of individuals with schizophrenia, very little is known about the experiences of the caregivers of these individuals. Caregivers are responsible for taking care of family members living with a serious mental illness on a daily basis. A better understanding of the influence this has on caregivers is essential especially in countries like South Africa with limited resources and support for patients and their caregivers or families. Caregivers' lived experiences will create greater awareness of caregivers' needs and how to best help caregivers.

Why have you been invited to participate?

You have been invited to participate in this study because you personally care for a family member living with schizophrenia. You will therefore be able to provide us with your subjective experience of caring for someone living with schizophrenia and what impact, whether positive or negative, it has on your life.

The research team hopes to have interviews with approximately 11 other caregivers as well, to tell us about their caregiving experience.

Where will the study be conducted?

The study will be conducted at the Schizophrenia Research Unit at Stikland Hospital in Bellville.

What will your responsibilities be during this part of the study?

As participant you will be asked to share as openly and freely, as you want; your experiences of being a caregiver. The study will be divided in to three parts that will take place over three sessions – *session 1, session 2, and session 3*. Each session will be approximately 60-90 minutes in duration.

In this session (session 1), you will be asked to participate in an individual interview and talk about your experiences of caring for someone living with schizophrenia. Only you and the researcher will be present and you will be asked to talk to the researcher for approximately an hour. The interview will be a once-off appointment.

However, after this interview, you will also be asked to attend a second interview at the same location. If you agree, I will ask you to take a camera home with you and to take pictures for

part of the research. The pictures will deal with topics that we have discussed in our interview. Before the second meeting the researcher will collect the camera from you and develop the pictures that you have taken. At the second session (session 2) all or some of these photographs may be used for discussion.

Will you benefit from taking part in this research?

There will be no direct personal benefit from participating, however you may help many healthcare providers and policy makers gain a better understanding of the experiences and needs of caregivers and how to provide adequate support.

Are there in risks involved in your taking part in this research?

No there are no risks involved in your taking part in this study. You are also free to decline to talk about issues during the interview that you are not comfortable to talk about. Should for some reason you feel that a topic discussed during the interview caused you emotional distress to the extent that you would like to talk to a professional, the researcher will assist you to find and pay for up to six psychological treatment services.

Also should you decline to participate in this study it will in no way jeopardize or have no negative consequences whatsoever.

Who will have access to your medical records?

We will not have access to your medical records or any other personal records. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. The interview will be audio-recorded and transcribed verbatim and will be confidential. Only the researcher and his supervisor will have access to the transcriptions. For this, all the information collected in this session will be stored on the researcher's password protected computer. Also your name and surname will not be used in any of the data collected during the interviews. You will be given a pseudonym (and not your name and surname) that will be linked to your data.

Please note that the information collected during the interviews will be used in future publications in academic journals and in a dissertation. The information may furthermore also be presented at academic events, such as conferences or academic lectures. However,

your information is anonymous and no-one will be able to link the data collected through the interview with your name and surname.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport and meal costs will be covered for each study visit. For this, the researcher will give you an amount of R150 at the end of this session. There will be no costs involved for you, if you do take part in this study.

Is there anything else that you should know or do?

- You can contact Divan Rall (email address divanrall@yahoo.com; tel. 072 597 8626) or Prof. Leslie Swartz (email address lswartz@sun.ac.za; tel. 021-808 3446) if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I ……..……. agree to take part in a research study entitled: Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa

I will be available to take part in part 1 of the study. (please tick the box with a "X"):

□ I want to participate in the semi-structured interview and give permission that my story may be audio-recorded and used for study purposes.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…..……. on (*date*) ……...…….. 2016.

....

Signature of participant **Signature of witness**

Declaration by investigator

I *(name)* ……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2016.

....

Signature of investigator **Signature of witness**

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR SESSION 2 AND SESSION 3

TITLE OF THE STUDY: Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa

REFERENCE NUMBER: S16/07/130

PRINCIPAL INVESTIGATOR OF STUDY: Divan Rall (under the supervision of Professor Leslie Swartz)

ADDRESS: Wilcocks Building, Stellenbosch University, Stellenbosch

CONTACT NUMBER:

Tel: 021 808 3446 (Department of Psychology at Stellenbosch University)

Tel: 021 938 9207 (Health Research Ethics Committee at Stellenbosch University)

Tel: 021 910 3605 (Stikland study unit)

You are being invited to take part in a research project about the experiences of someone caring for a family member living with schizophrenia.

Please take some time to read the information presented here, which will explain the details of this study. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this study all about and why is it important?

Although, some research has been done on the experiences of individuals with schizophrenia, very little is known about the experiences of the caregivers of these individuals. Caregivers are responsible for taking care of family members living with a serious mental illness on a daily basis. A better understanding of the influence this has on caregivers is essential especially in countries like South Africa with limited resources and support for patients and their caregivers or families. Caregivers' lived experiences will create greater awareness of caregivers' needs and how to best help caregivers.

Why have you been invited to participate?

You have been invited to participate in this study because you personally care for a family member living with schizophrenia. You will therefore be able to provide us with your subjective experience of caring for someone living with schizophrenia and what impact, whether positive or negative, it has on your life.

Where will the study be conducted?

The study will be conducted at the Schizophrenia Research Unit at Stikland Hospital in Bellville.

What will your responsibilities be in this part of the study?

As participant you will be asked to share as openly and freely, as you want; your experiences of being a caregiver. As mentioned earlier in this session, the study will be divided in to three parts that will take place over three sessions – *session 1, session 2, and session 3*.

If you agree to participate in session 2, I will now train you how to use a camera that will be provided to you. I will ask you to take the camera home with you, to take pictures for part of the research. The pictures will deal with topics that we have discussed in our interview. However, you will be asked not to capture a photo of any other individual (for example: other family members, friends, or any other person in your community) who are not part of this study. I will also collect the camera from you before the second appointment to develop the photos that you have taken. I will arrange this meeting with you at a time and location that suits you best (for example, collecting the camera from you at your home or workplace).

In the second meeting we will have a discussion about the photos that you have taken and choose to talk about. The study will benefit by the inclusion and discussing of the

photographs that you take – it will allow the researcher to get a better idea of your experiences of being a caregiver of a person with schizophrenia.

Only you and the researcher will be present and you will be asked to talk to the researcher for approximately an hour at a time that suits you best. This session will be a once-off appointment.

The last part of this study will occur during session 3. In session 3, you will be invited to a group meeting with other caregivers, just like you. The researcher of this study will report back the findings that he has found after session 1 and session 2. There will also be some photos that you and the other caregivers have taken on display. There will be an opportunity for all caregivers to discuss the photos with each other.

Will you benefit from taking part in this research?

There will be no direct personal benefit from participating, however you may help many healthcare providers and policy makers gain a better understanding of the experiences and needs of caregivers and how to provide adequate support.

Are there in risks involved in your taking part in this research?

No there are no risks involved in your taking part in this study. You are also free to decline to talk about issues during the interviews that you are not comfortable to talk about. Should for some reason you feel that a topic discussed during these sessions caused you emotional distress to the extent that you would like to talk to a professional, the researcher will assist you to find and pay for up to six psychological treatment services.

Also should you decline to participate in this study it will in no way jeopardize your participation in the larger study.

Who will have access to your medical records?

We will not have access to your medical records or any other personal records. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

The discussion of photos will be audio-recorded and transcribed verbatim and will be confidential. Only the researcher and his supervisor will have access to the transcriptions and

the photographs that you have captured. Again, your name and surname will not be used in any of the data collected during the interviews. You will be given a pseudonym (and not your name and surname) that will be linked to your data. All information collected in this research will be stored on a password protected computer of the researcher. The photos will be stored in a lock protected cabinet of the researcher. It is also your right to obtain one copy of any photograph that you have taken, if you wish.

Please note that the information and the photographs collected during the interviews will be used in future publications in academic journals and in a dissertation. The information and photographs may furthermore also be presented at academic events, such as conferences or academic lectures. However, your information is anonymous and no-one will be able to link the data collected through the interview with your name and surname. You also have the right to inform the researcher at any time if you wish that a particular photo should not be used for study and other academic purposes.

The research team wants you to know that we promise to keep your identity, information and story anonymous and confidential, as described above. However, we cannot guarantee that the other caregivers, which you will meet during session three, will do the same, as they may share stories with other that you do not know of.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport and meal costs will be covered for each study visit. For this, the researcher will give you an amount of R150 at the end of session 2, and an amount of R150 at the end of session 3. There will be no costs involved for you, if you do take part in this study.

Is there anything else that you should know or do?

- You can contact Divan Rall (email address divanrall@yahoo.com; tel. 072 597 8626) or Prof. Leslie Swartz (email address lswartz@sun.ac.za; tel. 021-808 3446) if you have any further queries or encounter any problems.
- You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.

- You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I ……..……. agree to take part in a research study entitled: Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa

I will be available to take part in the study. I want to be part of the following sessions (please tick the applicable boxes with an "X"):

□ Session 2: Discussing the photographs that I have taken and that my story may be audio-recorded and used for study purposes.

□ Session 3: The feedback session and group discussion. I also give permission for this session to be audio-recorded, and my contribution in this session may be used for study purposes.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- All photos that I have captured and choose to discuss may be used for academic purposes as described in this form. I am also aware that I may ask at any time for a particular photo(s) to be excluded from analysis or further academic purposes.
- I understand that I have the right to obtain one copy of any photograph that I have captured and will ask the researcher to provide me with this copy during or at the conclusion of session 2.

- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2016.

....

Signature of participant **Signature of witness**

Declaration by investigator

I *(name)* ……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use a interpreter. (*If a interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2016.

....

Signature of investigator **Signature of witness**

INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE STUDY: Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa

REFERENCE NUMBER: S16/07/130

PRINCIPAL INVESTIGATOR OF STUDY: Divan Rall (under the supervision of Professor Leslie Swartz)

ADDRESS: Wilcocks Building, Stellenbosch University, Stellenbosch

CONTACT NUMBER:

Tel: 021 808 3446 (Department of Psychology at Stellenbosch University)

Tel: 021 938 9207 (Health Research Ethics Committee at Stellenbosch University)

Tel: 021 910 3605 (Stikland study unit)

Your family member is invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project.

Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you may be involved. Also, your family member's participation is **entirely voluntary** and they are free to decline to participate. If you or your family member says no, this will not affect you negatively in any way whatsoever. You are also free to ask your family member to withdraw from the study at any point, even if you do agree that they may take part in this study.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

Although, some research has been done on the experiences of individuals with schizophrenia, very little is known about the experiences of the caregivers of these individuals. Caregivers are responsible for taking care of family members living with a serious mental illness on a daily basis. A better understanding of the influence this has on caregivers is essential especially in countries like South Africa with limited resources and support for patients and

their caregivers or families. Caregivers' lived experiences will create greater awareness of caregivers' needs and how to best help caregivers.

Why has your family member been invited to participate?

Your family member has been invited to participate in this study because they personally care for a family member living with schizophrenia. Your family member will therefore be able to provide us with your subjective experience of caring for someone living with schizophrenia and what impact, whether positive or negative, it has on their life.

Where will the study be conducted?

The study will be conducted at the Schizophrenia Research Unit at Stikland Hospital in Bellville.

What will your responsibilities be?

You will have no direct responsibility in the study processes. However, it will be required of you to accompany your family member to the first interview appointment. In this meeting, the researcher will explain to you, together with your family member, the nature of this study and what the study entails. The researcher will also explain to you what your family member's responsibilities in the study will be if both of you agree that your family member may participate in this project.

After this, your family member may be asked to accompany the researcher to an allocated room at the facility, where they will engage in an interview for approximately 60-90 minutes. In this time, you will be asked to wait for your family member in the waiting room. Refreshments will be available if you wish and you may help yourself with these while waiting for your family member to finish the interview. Thereafter, you and your family member may leave the facility. Lastly, this will be a once-off appointment; you will not be asked to accompany your family member for subsequent visits to partake in this study.

Will you or your family member benefit from taking part in this research?

There will be no direct personal benefit to you or your family member from participating in this study. However, if you agree that your family member may participate, you may help many healthcare providers and policy makers gain a better understanding of the experiences and needs of caregivers and how to provide adequate support.

Are there in risks involved in your taking part in this research?

No there are no risks involved if your family member agrees to partake in this study. You are also free to ask them to not talk about certain topics that involve you or aspects of your everyday life. Also should you decline your family member's participation in this study it will in no way jeopardize or have no negative consequences whatsoever.

Who will have access to your medical records?

We will not have access to your medical records or any other personal records. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

The interviews and discussion of photographs will be audio-recorded and transcribed verbatim and will be confidential. Only the researcher and his supervisor will have access to the transcriptions. For this, all the information collected in this session will be stored on the researcher's password protected computer. Also, your name and surname will not be used in any of the data collected during the interviews. You will be given a pseudonym (and not your name and surname) that will be linked to your data.

Furthermore, if your family member does agree to participate in this study, they may choose to take part in a total of three interviews sessions. The first two interview sessions will be appointments with a researcher. In the second interview your caregiver will discuss photographs that have been captured in an environment that includes aspects of your everyday life. In the third interview session, your caregiver may also discuss aspects of their caregiver experience with other caregivers. Additionally, some photos that may have been taken by your family member may be on display to other caregivers to start discussions between caregivers.

Please note that the information collected during the interviews will be used in future publications in academic journals and in a dissertation. The information may furthermore also be presented at academic events, such as conferences or academic lectures. However, your information is anonymous and no-one will be able to link the data collected through the interview with your name and surname.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study but your transport and meal costs will be covered for the study visit. For this, the researcher will give you an amount of R100 at the end of our meeting. There will be no costs involved for you, if you do agree for your family member to take part in this study.

Is there anything else that you should know or do?

You can contact Divan Rall (email address divanrall@yahoo.com; tel. 072 597 8626) or Prof. Leslie Swartz (email address lswartz@sun.ac.za; tel. 021-808 3446) if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.

You will receive a copy of this information and consent form for your own records.

Declaration by you

By signing below, I ……..……. agree that my family member, …….. may take part in a research study entitled Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa.

I declare that:

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is **voluntary** and I have not been pressurised to agree for my family member to take part in this study.

I may choose for my caregiver to withdraw from the study at any time and neither of us will be penalised or prejudiced in any way.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 2016.

Your signatureSignature of witness

Signature of family member who will participate in the study

Declaration by investigator

I *(name)* ……..…… declare that:

I explained the information in this document to ……..

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above

I did not use a interpreter.

Signed at (*place*) .....….....…….. on (*date*) ……...…….. 2005.

Signature of investigator Signature of witness

Afrikaans Consent Forms

DEELNEMER INLIGTINGSPAMFLET EN TOESTEMMINGSVORM VIR SESSIE 1

TITEL VAN DIE NAVORSING: ’n Verkenning van die versorger se ervaring: Die versorging van ’n gedeïnstitusionaliseerde indiwidu met skisofrenie in die Wes-Kaap, Suid-Afrika (“Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa”).

VERWYSINGSNOMMER: S16/07/130

HOOFONDERSOEKERS VAN DIE NAVORSING/NAVORSING: Divan Rall (onder toesig van professor Leslie Swartz)

ADRES: Wilcocks-gebou, Stellenbosch Universiteit, Stellenbosch

KONTAKNOMMERS:

Tel: 021 808 3446 (Departement Sielkunde by Stellenbosch Universiteit)

Tel: 021 938 9207 (Gesondheidsnavorsing-etiekomitee by Stellenbosch Universiteit)

Tel: 021 910 3605 (Stikland navorsingseenheid)

Jy word genooi om deel te neem aan ’n navorsingsprojek oor die ervarings van persone wat ’n gesinslid met skisofrenie versorg.

Neem gerus jou tyd om die inligting wat hierin gegee word rustig deur te lees aangesien dit die besonderhede van die navorsing sal verduidelik. Vra asseblief ook vir die navorsingspersoneel vrae oor enige aspek van die projek wat jy nie verstaan nie. Dit is baie belangrik dat jy tevrede moet wees dat jy goed verstaan wat die navorsing behels en hoe jy daarby betrek kan word. Jou deelname is heeltemal vrywillig en jy mag, as jy wil, weier om hieraan deel te neem. Indien jy aandui dat jy nie aan die projek wil deelneem nie, sal dit jou geensins benadeel nie. Dit staan jou ook vry om enige tyd deur die verloop van die navorsing te onttrek, al stem jy nou in om daaraan deel te neem.

Hierdie navorsing is deur die Gesondheidsnavorsing-etiekkomitee by Stellenbosch Universiteit goedgekeur en dit sal volgens die etiese riglyne en beginsels van die internasionale Deklarasie van Helsinki, die Suid-Afrikaanse Riglyne vir Goeie Mediese Praktyk en die Mediese Navorsingsraad se etiese riglyne vir navorsing gedoen word.

Waaroor gaan die navorsing en waarom is dit belangrik?

Alhoewel daar reeds navorsing gedoen is oor die ervarings van mense met skisofrenie, is daar min bekend oor die ervarings van die versorgers van hierdie indiwidue. Versorgers is verantwoordelik vir die daaglikse versorging van gesinslede met ernstige sielkundige ongesteldhede. ’n Beter begrip van die invloed wat dit op versorgers het, is noodsaaklik, veral in lande soos Suid-Afrika met beperkte hulpbronne en ondersteuning vir skisofrene en hul versorgers en gesinne. Kennis van die daaglikse ervarings van versorgers sal ’n groter bewustheid van die behoeftes van versorgers en hoe om hulle te ondersteun, bepaal.

Waarom is jy genooi om deel te neem?

Jy is genooi om aan hierdie navorsing deel te neem omdat jy ’n gesinslid met skisofrenie versorg. Daarom sal jy vir ons kan vertel wat jou persoonlike ervaring is ten opsigte van die versorging van ’n skisofreen en of dit jou lewe positief of negatief beïnvloed.

Die navorsinspan hoop om onderhoude te voer met ongeveer 11 ander versorgers wat ook bereid sal wees om hul ervarings as versorgers met ons te deel.

Waar sal die navorsing gedoen word?

Die navorsing sal by die skisofrenie navorsingseenheid by Stikland hospitaal in Belville gedoen word.

Jou verantwoordelikhede tydens hierdie deel van die navorsing.

Jy as deelnemer sal versoek word om so openlik en eerlik as wat jy wil jou ervarings as versorger te deel. Die navorsing word in drie dele verdeel wat tydens drie sessies – sessie 1, sessie 2 en sessie 3 – gedoen sal word.

Tydens hierdie sessie (sessie 1) sal jy gevra word om deel te neem aan ’n indiwiduele onderhoud waartydens jy sal praat oor jou ervarings as ’n versorger van ’n skisofreen. Slegs jy en die navorser sal teenwoordig wees en jy sal gevra word om vir ongeveer een uur lank met die navorser te gesels oor jou ervarings as versorger van ’n gesinslid met skisofrenie. Hierdie onderhoud is ’n eenmalige geleentheid.

Na hierdie eerste onderhoud (sessie 1) sal jy versoek word om ’n tweede onderhoud by dieselfde plek by te woon. Indien jy hiertoe instem sal ons jou vra om ’n kamera saam met jou huis toe te neem en foto’s te neem wat as deel van die navorsing gebruik gaan word. Die foto’s sal handel oor die onderwerpe wat ons tydens ons eerste onderhoud bespreek het. Voor die tweede onderhoud sal die navorser die kamera by jou kom haal en die foto’s wat jy geneem het ontwikkel. Tydens die tweede sessie (sessie 2) sal sommige van of al die foto’s wat jy geneem het vir die bespreking gebruik word.

Is daar vir jou persoonlike voordeel omdat jy aan die navorsing deelneem?

Daar is geen direkte persoonlike voordeel verbonde aan jou deelname aan die navorsing nie, maar deur daaraan deel te neem kan jy moontlik vir baie gesondheidsorgvoorsieners en beleidmakers help om die ervarings en behoeftes van versorgers beter te verstaan en beter te beplan hoe om sinvolle ondersteuning aan versorgers te bied.

Is daar enige risiko’s aan jou deelname aan die navorsing verbonde?

Nee, daar is geen risiko’s verbonde aan jou deelname aan die navorsing nie. Jy mag ook tydens die onderhoude weier om te praat oor aspekte waaroor jy sou verkies om nie te praat nie. Indien jy om een of ander rede sou voel dat ’n onderwerp wat tydens die onderhoud bespreek is vir jou in so ’n mate emosioneel ontstel het dat jy graag hieroor met ’n professionele persoon wil gesels, sal die navorser jou help om ’n geskikte afspraak te maak en betaal vir ses sielkundige behandelings.

Indien jy egter verkies om nie aan hierdie navorsing deel te neem nie sal dit op geen wyse jou deelname aan die groter navorsing benadeel nie.

Wie sal toegang hê tot jou mediese verslae?

Ons sal geen toegang hê tot jou mediese verslae of enige ander persoonlike verslae nie. Alle inligting wat in verband met hierdie navorsing versamel word en wat met jou persoonlik verbind kan word, sal as vertroulik beskou word en sal slegs met jou persoonlike verlof openbaar gemaak word soos dit deur die wet vereis word. ’n Oudio-opname sal van die onderhoud gemaak word en jou woorde sal woord-vir-woord neergeskryf word en sal steeds as vertroulik hanteer word. Slegs die navorser en sy navorsingleier sal toegang hê tot die geskrewe inhoud van jou onderhoud. Vir die doel sal hierdie en al die inligting wat tydens hierdie sessie versamel word gestoor word op die wagwoord-beskermde rekenaar van die navorser. Verder sal jou naam en van nie gebruik word in enige inligting wat tydens die onderhoud met jou versamel is nie. ’n Skuilnaam (en nie jou eie naam en van nie) sal aan jou inligting gekoppel word.

Neem asseblief kennis dat die inligting wat tydens onderhoude versamel is, gebruik sal word in toekomstige artikels in akademiese tydskrifte en in ’n verhandeling. Daarbenewens mag die inligting ook tydens akademiese geleenthede soos byvoorbeeld, konferensies gebruik word. Jou inligting bly egter anoniem en niemand sal die inligting wat tydens die onderhoud met jou versamel is met jou naam en van kan verbind nie.

Sal jy betaal word om aan hierdie navorsing deel te neem en is daar vir jou onkoste betrokke omdat jy deelneem?

Nee, jy sal nie betaal word om deel te neem aan hierdie navorsing nie, maar jou vervoer- en ete-onkostes sal vir elke sessiebesoek gedek word. Hiervoor sal die navorser vir jou R150 gee aan die einde van die sessie. Daar sal geen onkoste vir jou wees omdat jy aan die navorsing deelneem nie.

Is daar enige iets anders wat jy moet weet of doen?

Kontak gerus vir Divan Rall (e-posadres **divanrall@yahoo.com**; tel. 072 597 8626) of prof. Leslie Swartz (e-posadres **lswartz@sun.ac.za**; tel. 021-808 3446) indien jy enige verdere vrae het of as jy enige probleme het.

Jy kan die Gesondheidsnavorsing-etiekkomitee by 021-938 9207 skakel indien jy enige bekommernisse of klagtes het wat nie behoorlik deur die navorser hanteer is nie.

Jy sal ’n getekende afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir jou eie rekords.

Verklaring deur deelnemer

Deur hieronder te teken, stem ek, ……..……. in om deel te neem aan ’n navorsingsprojek met die titel *’n Verkenning van die versorger se ervaring: Die versorging van ’n gedeïnstitusionaliseerde indiwidu met skisofrenie in die Wes-Kaap, Suid-Afrika (“Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa”)*

Ek is beskikbaar om deel te neem aan sessie 1 van die navorsing. (Merk asseblief die onderstaande blokkie met ’n “X”):

□ Ek is bereid om deel te neem aan die semi-gestruktureerde onderhoud en gee hiermee my toestemming dat daar ’n oudio-opname van my antwoorde gemaak mag word en dat die opname gebruik kan word vir die doeleindes van die navorsing.

Ek verklaar hiermee dat:

Ek die inligtingspamflet en toestemmingsvorm gelees het of dat dit aan my voorgelees is en dat dit geskryf is in ’n taal waarin ek vlot is en waarin ek tuis voel.

Ek die geleentheid gehad het om vrae te vra en dat my vrae sinvol beantwoord is.

Ek verstaan dat my deelmame aan hierdie navorsing vrywillig is en dat ek nie gedwing is om daaraan deel te neem nie.

Ek enige tyd mag besluit om die navorsingsprojek te verlaat en dat ek nie daardeur op enige wyse gestraf of benadeel sal word nie.

Ek, voordat die navorsingsprojek afgehandel is, versoek mag word om nie langer deel van die navorsing te wees nie, indien die navorsingdokter of die navorser van mening is dat dit vir my die beste sal wees om nie langer betrokke te wees nie, of as ek die navorsingsplan nie volg soos wat ek ondernem het om dit te doen nie.

Geteken te (*plek*) .....…..…….. op (*datum*) ……...…….. 2016.

Handtekening van deelnemer Handtekening van getuie

Onderneming deur die ondersoeker

Ek *(naam)* ……..…… verklaar dat:

Ek die inligting in hierdie dokument verduidelik het aan

……..

Ek hom/haar aangemoedig het om vrae te vra en dat ek voldoende tyd gebruik het om die vrae volledig te beantwoord.

Ek tevrede is dat hy/sy al die aspekte van die navorsing, soos wat dit hierin verduidelik word, volledig verstaan.

Ek het/het nie ’n tolk gebruik nie. (*Indien ’n tolk gebruik word moet die tolk die onderstaande verklaring teken.*)

Geteken te (*plek*) .....….....…….. op (*datum*) ……...…….. 2016.

Handtekening van ondersoeker Handtekening van getuie

DEELNEMER INLIGTINGSPAMFLET EN TOESTEMMINGSVORM VIR SESSIE 2 EN SESSIE 3

TITEL VAN DIE NAVORSING: ’n Verkenning van die versorger se ervaring: Die versorging van ’n gedeïnstitusionaliseerde indiwidu met skisofrenie in die Wes-Kaap, Suid-Afrika (“Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa”).

VERWYSINGSNOMMER: S16/07/130

HOOFONDERSOEKERS VAN DIE NAVORSING: Divan Rall (onder toesig van professor Leslie Swartz)

ADRES: Wilcocks-gebou, Stellenbosch Universiteit, Stellenbosch

KONTAKNOMMERS:

Tel: 021 808 3446 (Departement Sielkunde by Stellenbosch Universiteit)

Tel: 021 938 9207 (Gesondheidsnavorsing-etiekomitee by Stellenbosch Universiteit)

Tel: 021 910 3605 (Stikland navorsingseenheid)

Jy word genooi om deel te neem aan ’n navorsingsprojek oor die ervarings van persone wat ’n gesinslid met skisofrenie versorg.

Neem gerus jou tyd om die inligting wat hierin gegee word rustig deur te lees aangesien dit die besonderhede van die navorsing sal verduidelik. Vra asseblief ook vir die navorsingspersoneel vrae oor enige aspek van die projek wat jy nie verstaan nie. Dit is baie belangrik dat jy tevrede moet wees dat jy goed verstaan wat die navorsing behels en hoe jy daarby betrek kan word. Jou deelname is heeltemal vrywillig en jy mag, as jy wil, weier om hieraan deel te neem. Indien jy aandui dat jy nie aan die projek wil deelneem nie, sal dit jou geensins benadeel nie. Dit staan jou ook vry om enige tyd deur die verloop van die navorsing te onttrek, al stem jy nou in om daaraan deel te neem.

Hierdie navorsing is deur die Gesondheidsnavorsing-etiekkomitee by Stellenbosch Universiteit goedgekeur en dit sal volgens die etiese riglyne en beginsels van die

internasionale Deklarasie van Helsinki, die Suid-Afrikaanse Riglyne vir Goeie Mediese Praktyk en die Mediese Navorsingsraad se etiese riglyne vir navorsing gedoen word.

Waaroor gaan die navorsing en waarom is dit belangrik?

Alhoewel daar reeds navorsing gedoen is oor die ervarings van mense met skisofrenie, is daar min bekend oor die ervarings van die versorgers van hierdie indiwidue. Versorgers is verantwoordelik vir die daaglikse versorging van gesinslede met ernstige sielkundige ongesteldhede. 'n Beter begrip van die invloed wat dit op versorgers het, is noodsaaklik, veral in lande soos Suid-Afrika met beperkte hulpbronne en ondersteuning vir skisofrene en hul versorgers en gesinne. Kennis van die daaglikse ervarings van versorgers sal 'n groter bewustheid van die behoeftes van versorgers en hoe om hulle te ondersteun, bepaal.

Waarom is jy genooi om deel te neem?

Jy is genooi om aan hierdie navorsing deel te neem omdat jy 'n gesinslid met skisofrenie versorg. Daarom sal jy vir ons kan vertel wat jou persoonlike ervaring is ten opsigte van die versorging van 'n skisofreen en of dit jou lewe positief of negatief beïnvloed.

Die navorsinspan hoop om onderhoude te voer met ongeveer 11 ander versorgers wat ook bereid sal wees om hul ervarings as versorgers met ons te deel.

Waar sal die navorsing gedoen word?

Die navorsing sal by die skisofrenie navorsingseenheid by Stikland hospitaal in Belville gedoen word.

Jou verantwoordelikhede tydens hierdie deel van die navorsing.

Jy as deelnemer sal versoek word om so openlik en eerlik as wat jy wil jou ervarings as versorger te deel. Die navorsing word in drie dele verdeel wat tydens drie sessies – sessie 1, sessie 2 en sessie 3 – gedoen sal word.

Indien jy daartoe instem om aan sessie 2 van die navorsing deel te neem sal ek jou oplei om die kamera, wat aan jou gegee sal word, te gebruik. Ek sal jou vra om die kamera huis toe te neem en om foto's te neem wat as deel van die navorsing gebruik gaan word. Die foto's sal oor die onderwerpe wat ons in die onderhoud bespreek het wees. Jy sal egter versoek word

om geen ander indiwiduele foto's of groepfoto's (van byvoorbeeld ander gesinslede, vriende of enige ander persoon in jou gemeenskap) wat nie deel is van die navorsing te neem nie. Ek sal die kamera voor die tweede sessie by jou kom haal om die foto's wat jy geneem het te ontwikkel. Ek sal ons ontmoeting om die kamera te kry met jou reël op 'n plek en 'n tyd wat jou die beste pas (byvoorbeeld, ek kan met jou reël om die kamera by jou werk te kom haal as dit jou sou pas).

Tydens die tweede sessie sal ons die foto's wat jy geneem het en die wat jy verkies om oor te praat, bespreek. Die navorsing sal baat vind by die insluiting van die foto's wat jy geneem het en die bespreking wat jy oor die foto's wat jy geneem het met ons het – dit sal die navorser toelaat om 'n beter begrip te kry van jou ervarings as versorger van 'n persoon met skisofrenie.

Slegs jy en die navorser sal tydens die die tweede onderhoud teenwoordig wees en jy sal versoek word om vir ongeveer een uur met die navorser te gesels op 'n tyd wat jou die beste pas. Hierdie sessie is 'n eenmalige geleentheid.

Die laaste gedeelte van die navorsing sal tydens die derde sessie plaasvind. Vir sessie 3 sal jy genooi word om 'n groepsvergadering met ander versorgers net soos jy by te woon. Die navorser van die navorsingsprojek sal terugvoer verskaf oor sy bevindinge met betrekking tot sessies 1 en 2. Daar sal ook sommige van die foto's wat jy en die ander versorgers geneem het, uitgestal word. Daar sal ook geleentheid gegee word vir al die versorgers om die uitgestalde foto's met mekaar te bespreek.

Is daar vir jou persoonlike voordeel omdat jy aan die navorsing deelneem?

Daar is geen direkte persoonlike voordeel verbonde aan jou deelname aan die navorsing nie, maar deur daaraan deel te neem kan jy moontlik vir baie gesondheidsorgvoorsieners en beleidmakers help om die ervarings en behoeftes van versorgers beter te verstaan en beter te beplan hoe om sinvolle ondersteuning aan versorgers te bied.

Is daar enige risiko's aan jou deelname aan die navorsing verbonde?

Nee, daar is geen risiko's verbonde aan jou deelname aan die navorsing nie. Jy mag ook tydens die onderhoude weier om te praat oor aspekte waaroor jy sou verkies om nie te praat nie. Indien jy om een of ander rede sou voel dat 'n onderwerp wat tydens die onderhoud bespreek is vir jou in so 'n mate emosioneel ontstel het dat jy graag hieroor met 'n

professionele persoon wil gesels, sal die navorser jou help om ’n geskikte afspraak te maak en betaal vir ses sielkundige behandelings.

Indien jy egter verkies om nie aan hierdie navorsing deel te neem nie sal dit op geen wyse jou deelname aan die groter navorsing benadeel nie.

Wie sal toegang hê tot jou mediese rekords?

Ons sal geen toegang hê tot jou mediese rekords of enige ander persoonlike rekords nie. Alle inligting wat vir hierdie navorsing versamel word en wat met jou geïdentifiseer kan word sal vertroulik bly en sal slegs met jou verlof bekend gemaak word soos wat dit deur die wet vereis word.

Daar sal van die bespreking van die foto’s ’n oudio-opname gemaak word en jou woorde sal woord-vir-woord neergeskryf word maar dit sal steeds as vertroulik hanteer word. Slegs die navorser en sy studieleier sal toegang tot die transkripsie van jou woorde en die foto’s wat jy geneem het, hê. Weereens wil ons jou verseker dat jou naam en van nie gebruik sal word in enige van die inligting (data) wat tydens onderhoude met jou versamel is nie. Jy sal ’n skuilnaam ontvang (wat nie jou naam en van is nie) wat aan jou inligting (data) gekoppel word. Alle inligting wat tydens hierdie navorsingsprojek versamel word, sal op die wagwoord-beskermde rekenaar van die navorser gestoor word. Die foto’s sal in ’n geslote kabinet van die navorser gestoor word. Dit is ook jou reg om te vra vir een kopie van enige foto wat jy geneem het.

Neem asseblief kennis dat die inligting en foto’s wat tydens die onderhoude met jou versamel is, in die toekoms gebruik sal word vir publikasie in akademiese joernale en in ’n verhandeling. Daarbenewens is dit moontlik dat die foto’s en inligting ook tydens akademiese geleenthede, soos konferensies, gebruik sal word. Jou persoonlike inligting sal egter altyd onbekend wees aangesien die inligting anoniem sal bly en niemand die inligting aan jou naam en van sal kan koppel nie. Jy het die reg om die navorser enige tyd in te lig dat jy verkies dat ’n spesifieke foto nie vir die navorsing of vir ander akademiese doeleindes gebruik mag word nie.

Die navorsingspan wil ook graag hê dat jy moet weet dat ons belowe dat ons jou identiteit, inligting en storie as vertroulik sal beskou soos wat hierbo verduidelik word. Ons kan egter nie waarborg dat die ander versorgers wat jy tydens sessie 3 sal ontmoet, dieselfde sal doen nie, aangesien hulle moontlik stories met ander waarvan ons nie weet nie, sal deel.

Sal jy betaal word om aan hierdie navorsing deel te neem en is daar vir jou onkoste betrokke omdat jy deelneem?

Nee, jy sal nie betaal word om deel te neem aan hierdie navorsing nie, maar jou vervoer- en ete-onkostes sal vir elke sessiebesoek gedek word. Hiervoor sal die navorser vir jou 'n bedrag van R150 gee aan die einde van sessie 2 en 'n bedrag van R150 aan die einde van sessie 3. Daar sal geen onkoste vir jou wees omdat jy aan die navorsing deelneem nie.

Is daar enige iets anders wat jy moet weet of doen?

Kontak gerus vir Divan Rall (e-posadres **divanrall@yahoo.com**; tel. 072 597 8626) of prof. Leslie Swartz (e-posadres **lswartz@sun.ac.za**; tel. 021-808 3446) indien jy enige verdere vrae het of as jy enige probleme het.

Jy kan die Gesondheidsnavorsing-etiekkomitee by 021-938 9207 skakel indien jy enige bekommernisse of klagtes het wat nie behoorlik deur die navorser hanteer is nie.

Jy sal 'n getekende afskrif van hierdie inligtingspamflet en toestemmingsvorm ontvang vir jou eie rekords.

Verklaring deur deelnemer

Deur hieronder te teken, stem ek, ……..……. in om deel te neem aan ’n navorsingsprojek met die titel ’n Verkenning van die versorger se ervaring: Die versorging van ’n gedeïnstitusionaliseerde indiwidu met skisofrenie in die Wes-Kaap, Suid-Afrika (“Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa”)

Ek is beskikbaar om deel te neem aan die navorsing. Ek wil ook deelneem aan die onderstaande twee sessies (Merk asseblief die onderstaande blokkies met ’n “X”):

☐ Sessie 2: ’n Bespreking van die foto’s wat ek geneem het en dat daar van my storie ’n oudio-opname gemaak word en dit vir navorsingsdoeleindes gebruik mag word.

☐ Sessie 3: Die terugvoersessie en die groepbespreking. Ek gee ook verlof dat daar van hierdie sessie ’n oudio-opname gemaak word en dat my bydrae tot hierdie sessie gebruik mag word vir navorsingsdoeleindes.

Ek verklaar hiermee dat:

- Ek die inligtingspamflet en toestemmingsvorm gelees het of dat dit aan my voorgelees is en dat dit geskryf is in ’n taal waarin ek vlot is en waarin ek tuis voel.
- Ek die geleentheid gehad het om vrae te vra en dat my vrae sinvol beantwoord is.
- Ek verstaan dat my deelmame aan hierdie navorsing **vrywillig** is en dat ek nie gedwing is om daaraan deel te neem nie.
- Ek enige tyd mag besluit om die navorsingsprojek te verlaat en dat ek nie daardeur op enige wyse gestraf of benadeel sal word nie.
- Ek, voordat die navorsingsprojek afgehandel is, versoek mag word om nie langer deel van die navorsing te wees nie, indien die navorsingdokter of die navorser van mening is dat dit vir my die beste sal wees om nie langer betrokke te wees nie, of as ek die navorsingsplan nie volg soos wat ek onderneem het om dit te doen nie.

Geteken te (*plek*) .....…..…….. op (*datum*) ……...…….. 2016.

…… ……

Handtekening van deelnemer **Handtekening van getuie**

Onderneming deur die ondersoeker

Ek *(naam)* ……..…… verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan

  ……..
- Ek hom/haar aangemoedig het om vrae te vra en dat ek voldoende tyd gebruik het om die vrae volledig te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsing, soos wat dit hierin verduidelik word, volledig verstaan.

Geteken te (*plek*) .....….....…….. op (*datum*) ……....…….. 2016.

....

Handtekening van ondersoeker **Handtekening van getuie**

INFORMASIE PAMFLET EN TOESTEMMINGSVORM

TITEL VAN DIE NAVORSING: 'n Verkenning van die versorger se ervaring: Die versorging van 'n gedeïnstitusionaliseerde indiwidu met skisofrenie in die Wes-Kaap, Suid-Afrika ("Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa").

VERWYSINGSNOMMER: S16/07/130

HOOFONDERSOEKERS VAN DIE NAVORSING/NAVORSING: Divan Rall (onder toesig van professor Leslie Swartz)

ADRES: Wilcocks-gebou, Stellenbosch Universiteit, Stellenbosch

KONTAKNOMMERS:

Tel: 021 808 3446 (Departement Sielkunde by Stellenbosch Universiteit)

Tel: 021 938 9207 (Gesondheidsnavorsing-etiekomitee by Stellenbosch Universiteit)

Tel: 021 910 3605 (Stikland navorsingseenheid)

U familielid is uitgenooi om deel te neem in 'n navorsing projek. Asseblief neem 'n bietjie tyd om die inligting hier voorgelê te lees, wat die inligting van die projek sal verduidelik. Asseblief vra die studie personeel of dokter enige vrae oor enige deel van die projek wat u nie ten volle verstaan nie. Dit is baie belangerik dat u ten volle tevrede is en verstaan wat die navorsing behels en hoe u betrokke kan wees. Asook u familie lede wat deelneem is **geheel en al vrywillig** en hulle is vry om deelneming van hand te wys. As u of u familielid nee se, sal dit u nie negatief affekteer in enige manier hoegenaamd nie. U is ook vry om u familie lede te vra om te ontrek van die studie te enige tyd, selfs al stem u in dat hulle mag deelneem aan die studie.

Die studie was goedgekeur deur die **Gesondheids Navorsing Etiek Komitee by Stellenbosch Universiteit** en sal gedoen word volgens die etiese gidslyn en oorsprong van die Internasionale Verklaring van Helsinki, Suid Afrikaanse Riglyne vir Goeie Mediese Praktyk en die Mediese Navorsings Raad (MNR) Etiese Riglyne vir Navorsing

Waaroor gaan die navorsings studie?

Alhoewel sommige navorsing gedoen is op die ondervindings van individue met skisofrenie, is bitter min kennis bekend van die ondervindings van die versorgers of die individuele. Versorgers is verantwoordelik na die omsien van familie lede met 'n ernstige verstandelike siekte op 'n daaglikse

basis. ’n Beter verstaning van die invloed wat dit het op versorgers is noodsaaklik veral in lande soos Suid Afrika met beperkte bronne en ondersteuning van pasiënte en hulle versorgers of families. Versorgers’ se ervare ondervindings skep groter bewusmaking van versorgers’ belange en hoe om versorgers beter te help

Hoekom was u familielid uitgenooi om deel te neem?

U familielid is uitgenooi om deel te neem in die studie omdat hulle persoonlik omsien na ’n familielid wat lewe met skisofrenie. U familielid sal dus daarom in staat wees om ons te voorsien met u subjektiewe ondervindings van versorging vir iemand wat lewe met skisofrenie en watter impak, hoe ook al positief of negatief, dit op hulle lewe het.

Waar sal die studie Plaasvind?

Die studie sal plaasvind by die Skisofrenie Navorsing Eenheid by Stikland Hospitaal in Bellville

Wat sal u se verantwoordelikhede wees?

U sal geen direkte verantwoordelikhede hê in die studie proses nie. Alhoewel, dit behels word van u om u familielid te vergesel na die eerste onderhoud afspraak. In die vergadering sal die navorser aan u verduidelik, gesamentlik met u familielid, die aard van die studie en wat die studie behels. Die navorser sal ook aan u verduidelik wat u familielid se verantwoordelikhede in die studies sal wees indien beide instem dat u familielid mag deelneem in die projek.

Na dit. mag u familielid moontlik gevra word om die navorser na ’n toepaslike kamer by die fasiliteit te vergesel, waar hulle sal verkeur in ’n onderhoud vir ongeveer 60-90 minute in tyd, U sal gevra word om vir u familielid te wag in die wagkamer. Verversings sal beskikbaar wees indien u sou wens om uself te help terwyl u wag vir u familielid om klaar te maak met hul onderhoud. Daarna mag u en u familielid die fasiliteit verlaat. Laastens. Dit sal ’n eenmalige afspraak wees; u sal nie versoek word om u familielid te verteenwoordig met opvolgende besoeke om die studie by te woon nie

Sal u of u familielid voordeel trek deur deel van die studie te wees?

Daar sal geen direkte persoonlike baat wees aan u of u familielid vir julle deelname aan die studie nie. Alhoewel, as u sal instem dat u familielid mag deelneem, mag u help soveel moontlik dat voorsieners van gesondheidsorg en beleidmakers kry 'n beter begrip van die ondervindings en belange van versorgers en hoe om voldoende ondersteuning te voorsien.

Is daar enige risiko’s betrokke in u deelneming in die navorsing?

Nee daar is geen risiko’s betrokke as u familielid instem om deel te neem in die studie nie. U is ook welkom om hulle te vra om sekere onderwerpe te vermy wat u of aspekte van u aller daaglikse lewe

behels. Asook sou u, u familielid se deelneming in die studie afkeur sal u in geen omstandighede beïnvloed word of negatiewe gevolge hê hoegenaamd nie

Wie sal toegang tot u mediese rekords hê?

Ons sal nie toegang tot u mediese rekords of enige ander persoonlike rekords hê nie. Enige inligting wat verkry word in verband met die studie en wat geïdentifiseer kan word met u sal konfidensieel gehou word en sal slegs bekend gemaak word net met u toestemming of volgens wet.

Die onderhoude en gesprekke van foto's sal op band geneem word en verbatim getranskribeer word en sal vertroulik gehou word. Slegs die navorser en sy opsigter sal toegang tot die transkripsies hê. Vir dit al die inligting wat ingesamel word tydens die sessie sal op die navorser se geheimewoord beskermde rekenaar gestoor word. Asook, u naam en van sal nie gebruik word in enige inligting wat ingesamel word tydens onderhoude nie. U sal 'n skuilnaam gegee word (nie u regte naam en van nie) wat geheg sal word aan u inligting.

Verder, as u familielid instem om die studie te doen, mag hulle kies om deel te neem in 'n totaal van drie onderhoud sessies. Die eerste twee onderhoude sal plaasvind met 'n navorser. In die tweede onderhoud sal u versorger bespreek oor foto's wat geneem is in 'n omgewing wat aspekte van u aller daagse lewe insluit. In die derde onderhoud sessie, mag u versorger ook bespreek oor aspekte van hulle ondervinding met ander versorgers. Daarbenewens, sommige foto's wat dalk deur u familielid geneem was mag dalk getoon word aan ander versorgers om gesprek aan te moedig tussen versorgers.

Let wel dat die inligting wat versamel was tydens die onderhoude gebruik sal word vir toekomstige publikasies in akademiese dagboeke en in dissertasie. Die inligting mag verder ook voorgelê word by akademiese bykomstighede, soos konferensies of akademiese voorleggings. Alhoewel u inligting anoniem is en niemand die data wat tydens onderhoude versamel is met u naam of van kan assosieer nie

Sal u betaal word om deel te neem in die studie en is daar enige kostes aan verbonde?

Nee, u sal nie betaal word om deel te neem aan die studie nie maar u vervoer en verblyf sal gedek word tydens die studie besoeke. Vir die, sal die navorser u R100 aan die einde van elke vergadering gee. Daar sal geen kostes in verbonde wees vir u nie, as u in stem vir u familielid om deel te neem aan die studie.

Is daar enige iets anders wat u moet weet of doen?

- U kan Divan Rall kontak (e-pos adres **divanrall@yahoo.com** tel. 072 597 8626 of Prof. Leslie Swartz (e-pos **lswartz@sun.ac.za**; tel. 021-808 3446 as u enige verdere vrae het of probleme teëkom.
- U kan die Gesondheids Navorsing Etiese Komitee by 021-938-9207 as u enige bekommernisse of klagtes het wat nie regverdig toegespreek is by navorser nie.

U sal 'n afskrif ontvang van die inligting en toelatings vorm vir u eie rekords

Verklaring deur u

Die ondergetekende, Ek …….. stem in dat my familielid ……. Mag deel neem in ’n navorsing studie geregtig Verkenning die Versorger Ervaring: Versorging vir ’n ongeïnstitusionaliseerde individueel met skisofrenie in die Wes Kaap, Suid Afrika.

Ek verklaar dat:

- Ek het gelees of was voor gelees die inligting en toestemming vorm en dit is geskryf in ’n taal waarin ek vlod en gemaklik mee is.
- Ek het ’n beurt gehad om vrae te vra en al my vrae was tot die beste van vermoë beantwoorde.
- Ek verstaan dat om deel te neem in die studie is vrywillig en ek was nie geforseer om in te stem vir my familielid om deel te neem in die studie nie.
- Ek mag kies vir my versorger om te onttrek van die studie enige tyd en nie beide van ons sal gepenaliseer of geoordeel word in enige manier nie.

Geteken (*Plek*)……...op (*datum*)……....2016

....

U Handtekening **Handtekening van Getuie**

.....

Handtekening van familielid wat deel neem aan die studie

Verklaring van Ondersoeker

Ek *(naam)* ……..…… verklaar dat:

- Ek het inligting in hierdie dokument verduidelik aan……
- Ek het hom/haar aangemoedig om vrae te vra en genoegsame tyd gegee om hulle te beantwoord
- Ek is tevrede dat hy/sy ten volle verstaan alle aspekte van die navorsing, soos bespreek bo aan
- Ek het nie ’n Interpreteerder gebruik nie

Geteken (*plek*) .....….....…….. op (*datum*) ……...…….. 2016.

....

Handtekening van Inspekteer **Handtekening van Getuie**

Appendix D

Contracts of Confidentiality by Transcribers

Transcriber: Ms C Jansen Van Vuuren

CONTRACT OF CONFIDENTIALITY OF TRANSLATED/TRANSCRIBED MATERIALS

I, Divan Rall a Msc Psychology (research) student at the Department of Psychology am making use of outside contractors for the transcription of interviews for my Masters Degree research project titled: Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa. The confidentiality of these interviews may under no circumstances be compromised as this would break the contract of confidentiality that was agreed with each participant before the interviews commenced. As such, I am asking all transcribers to sign a binding contract assuring the Department of complete confidentiality concerning the content of the transcribed materials.

I, Carmin Jansen Van Vuuren, hereby undertake that under no circumstances will I share the content of the any of the interviews that were provided to me. I undertake to keep all narratives and communication between the researcher and the participant in complete confidence at all times and will return it to the primary investigator directly.

Signature: CJW Date: 5/10/2016

Full name: Carmin Jansen van Vuuren Telephone no: 0723663295

Email: carminjvv13@gmail.com Name of company: Self

Transcriber: Ms L.M Jones

CONTRACT OF CONFIDENTIALITY OF TRANSLATED/TRANSCRIBED MATERIALS

I, Divan Rall a Msc Psychology (research) student at the Department of Psychology am making use of outside contractors for the transcription of interviews for my Masters Degree research project titled: Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa. The confidentiality of these interviews may under no circumstances be compromised as this would break the contract of confidentiality that was agreed with each participant before the interviews commenced. As such, I am asking all transcribers to sign a binding contract assuring the Department of complete confidentiality concerning the content of the transcribed materials.

I, Lynda Mary Jones, hereby undertake that under no circumstances will I share the content of the any of the interviews that were provided to me. I undertake to keep all narratives and communication between the researcher and the participant in complete confidence at all times and will return it to the primary investigator directly.

Signature:  Date: 06 September 2016

Full name: Lynda Mary Jones Telephone no: 042 2920311/0725910052

Email: intelliverb@gmail.com Name of company: Intelligent Verbatim

Appendix E

Ethical Approval

Approved with Stipulations

Response to Modifications- (New Application)

31-Aug-2016

Rall, Divan D

Ethics Reference #: S16/07/130

Title:

Exploring the Caregiver Experience: Caring for a Deinstitutionalised Individual with Schizophrenia in the Western Cape, South Africa

Dear Mr Divan Rall,

The **Response to Modifications** - ***(New Application)*** received on **19-Aug-2016**, was reviewed by members of **Health Research Ethics Committee 2** via Expedited review procedures on **31-Aug-2016**. Please note the following information about your approved research protocol:

Protocol Approval Period: **31-Aug-2016 -30-Aug-2017**

The Stipulations of your ethics approval are as follows:

1. The interview schedule of the study asks for information about the patient suffering from schizophrenia. Similarly the taking and discussion of photographs and the focus group discussions amongst other caregivers may reveal personal information about the index patients. These may then imply a breach of confidentiality, unless the index patient suffering from schizophrenia is informed and also provides consent for these two components of the study procedure. Please include specific informed consent for these procedures.

Please remember to use your **protocol number** (**S16/07/130**) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Helene Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: www.sun.ac.za/rds

If you have any questions or need further assistance, please contact the HREC office at.

Included Documents:

3. Proposal - Caregiver Burden Schizophrenia (Divan Rall).docx

20160822 MOD Cover letter

7.1. Investigator Declaration V4.2 (Eng) Divan Rall completed 1.docx

5.1 Divan Rall IFC Session 1 DR.docx

4. Divan Rall Study Summary DR.docx

20160822 MOD Protocol

1. HREC Application Form V9 14 April 2016 (Eng) Divan Rall (prof Swartz).docx

CV L Swarts

20160822 MOD Consent form

2. General Checklist(Eng)_V2.1 April 2016 DR.doc

6. Curriculum Vitae of Divan Rall.doc

20160822 MOD HREC Mods letter

7.2. Supervisor Declaration V4.2 (Eng) Prof Swartz.docx

5.2 Divan Rall IFC Sessions 2-3 DR.docx

0. Cover letter Divan Rall.docx

Sincerely,

Francis Masiye

HREC Coordinator

Health Research Ethics Committee 2

Investigator Responsibilities

Protection of Human Research Participants

Some of the responsibilities investigators have when conducting research involving human participants are listed below:

1.Conducting the Research. You are responsible for making sure that the research is conducted according to the HREC approved research protocol. You are also responsible for the actions of all your co-investigators and research staff involved with this research.

2.Participant Enrolment. You may not recruit or enrol participants prior to the HREC approval date or after the expiration date of HREC approval. All recruitment materials for any form of media must be approved by the HREC prior to their use. If you need to recruit more participants than was noted in your HREC approval letter, you must submit an amendment requesting an increase in the number of participants.

3.Informed Consent. You are responsible for obtaining and documenting effective informed consent using **only** the HREC-approved consent documents, and for ensuring that no human participants are involved in research prior to obtaining their informed consent. Please give all participants copies of the signed informed consent documents. Keep the originals in your secured research files for at least fifteen (15) years.

4.Continuing Review. The HREC must review and approve all HREC-approved research protocols at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the HREC approval of the research expires, **it is your responsibility to submit the continuing review report in a timely fashion to ensure a lapse in HREC approval does not occur.** If HREC approval of your research lapses, you must stop new participant enrolment, and contact the HREC office immediately.

5.Amendments and Changes. If you wish to amend or change any aspect of your research (such as research design, interventions or procedures, number of participants, participant population, informed consent document, instruments, surveys or recruiting material), you must submit the amendment to the HREC for review using the current Amendment Form. You **may not initiate** any amendments or changes to your research without first obtaining written HREC review and approval. The **only exception** is when it is necessary to eliminate

apparent immediate hazards to participants and the HREC should be immediately informed of this necessity.

6.Adverse or Unanticipated Events. Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research related injuries, occurring at this institution or at other performance sites must be reported to the HREC within **five (5) days** of discovery of the incident. You must also report any instances of serious or continuing problems, or non-compliance with the HRECs requirements for protecting human research participants. The only exception to this policy is that the death of a research participant must be reported in accordance with the Stellenbosch Universtiy Health Research Ethics Committee Standard Operating Procedures www.sun025.sun.ac.za/portal /page/portal/Health_Sciences/English/Centres%20and%20Institutions/Research_Development_Support/Ethics/Application_package All reportable events should be submitted to the HREC using the Serious Adverse Event Report Form.

7.Research Record Keeping. You must keep the following research-related records, at a minimum, in a secure location for a minimum of fifteen years: the HREC approved research protocol and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence from the HREC.

8.Reports to the MCC and Sponsor. When you submit the required annual report to the MCC or you submit required reports to your sponsor, you must provide a copy of that report to the HREC. You may submit the report at the time of continuing HREC review.

9.Provision of Emergency Medical Care. When a physician provides emergency medical care to a participant without prior HREC review and approval, to the extent permitted by law, such activities will not be recognised as research nor will the data obtained by any such activities should it be used in support of research.

10.Final reports. When you have completed (no further participant enrolment, interactions, interventions or data analysis) or stopped work on your research, you must submit a Final Report to the HREC.

11.On-Site Evaluations, MCC Inspections, or Audits. If you are notified that your research will be reviewed or audited by the MCC, the sponsor, any other external agency or any internal group, you must inform the HREC immediately of the impending audit/evaluation.

Appendix F

A Description of the Participants

Cassey

Cassey is a mother of three; one daughter and two sons. Both her sons have been diagnosed with schizophrenia. At the time of the interviews Cassey informed me that she was retired and has been caring for one of her sons with schizophrenia for the past 15 years. Her son, divorced and unemployed, lives in a flatlet on Cassey's premises. This explained why Cassey only cares for him on a part-time basis. While Cassey explained that she was not actively caring for her other son who also has schizophrenia, it struck me how she frequently shared narratives related to him, rather than of her son who was in her care. Related to caregiving, Cassey shared different aspects of caregiver burden and the coping strategies she utilised when providing care for her son. She particularly found her son's illness related behaviours that she is exposed to, such as delusions, challenging. Furthermore, that her son's lack of insight about his illness introduces various difficulties, as it diminishes his willingness to commit to professional healthcare. However, to cope with these burdens she shared how her husband and other family members assist her by offering emotional and social support. Furthermore, Cassey utilised various problem focused coping strategies such as making use of professional healthcare and police services at times when her son became problematic in the caregiving environment. Emotion focused coping strategies were also exercised by Cassey. Here, she described herself as a "strong" person and she has confidence in her ability to care for her son. She attributed these qualities to some of her past life events that contributed in forming her emotional strength and confidence. In the interview, Cassey shared different past personal life burdens with me. I reflect on two of these burdens below. First, Cassey is currently in her second marriage as she divorced her first husband. She described her first husband as physically and emotionally abusive. After divorcing her first husband her children moved in with her at the time. It was also during this period that her first husband committed suicide, and Cassey believes that it was this act that stimulated the onset of schizophrenia in one of her sons, as he witnessed the events related to his father's suicide. Second, Cassey cautiously shared that she was raped as a teenager, but that she has never before disclosed this information to anyone. Therefore, it was not surprisingly when she voiced the words, "*Ek sou 'n beter lewe wou gehad het*" *("I would have wanted a better life"*). As researcher what struck me was the sense of trust that developed between us in this session, as she has never met me before, yet, trusted me with one of her deepest, longstanding

personal difficulties. Despite these difficult times, Cassey has bounced back in life – by overcoming the challenging times and by creating a better life for herself; "*Ek sal nie sê my lewe is weg nie, ek sal sê ek is okay daarmee*" (*"I will not say that my life is gone, I will say that I am okay with it")*.

Maryna

Maryna is a mother of three sons and, at the time of the interview, was married to her first husband. All five individuals stay together in the same house. During the interviews it became known that at least one of her son's has been diagnosed with schizophrenia. Another son was, at the time of the interviews, in psychiatric observation in a pre-discharge ward for people with schizophrenia. Her third and youngest son also displayed symptoms of an undiagnosed mental disorder at the time. During the informed consent procedure I perceived her son to be in a psychotic state as he displayed persecutory delusions. Interestingly, during the interviews Maryna did not view her son as a person who has schizophrenia. She believed that nothing was strange in his thinking, but rather that it was the environment (his job) that caused his delusions, as he has been dismissed from his work. I was caught off-guard by this as I expected that she would refer to her son as a schizophrenia patient. It is my suspicion that Maryna might be in denial about her son(s)'s illness and the impact it has on her life. Nevertheless, I accepted her point of view and the interview continued; however, the word "schizophrenia" was not used once throughout the interview. Maryna did not believe that her son had schizophrenia, yet she reported various caregiving burdens. For example, she reported patient violent behaviours at home; conflict between the patient and other family members; and patient dependency. Furthermore, Maryna also shared how she has to prepare food for her son and how she has to attend to the cleaning of her son's living environment and his belongings, as he, at times, is not able to do this independently. Maryna further voiced the importance of social support in her life; especially from community members, as she did not choose to reach out and accept support from other family members outside the caregiving environment. She also elaborated on the fundamental role that religion plays to help her cope during difficult times – *"dan kan ek nie dink ek het dit alleen, ek meen God se krag was altyd by ons" ("then I can't think I did it alone, I mean God's strength was always with us"*).

Skollie

Skollie, together with his wife Sheila, was part of the one caregiver-couple who participated in my study. Skollie is a father of two children, both of whom have been diagnosed with schizophrenia. His daughter was married, and together with her husband resided on the premises of Skollie at the time of the interviews. Skollie's son was living at a community based schizophrenia care centre, but was allowed to visit Skollie and his wife over weekends. What struck me during his interview was the manner in which he narrated the impact of the illness on his and his children's lives. For me, the summary of his caregiving experience and having children with schizophrenia was summarised by our following interaction towards the end of the interview:

> Skollie: *Dis ŉ damn onplesierige... Vir ŉ ouer dis ŉ hartsterkende ondervinding. Dis ŉ vloek, daardie illness. Ek wil nie my eie vyand hê hy moet die mental illness hê nie.*
> Divan: *Mm hm. Jou hele lewe word om ver gegooi.*
> Skollie: *I wouldn't wish it on my own bloody dog, this mental illness*.
>
> Skollie: *It's a damn unpleasant… For a parent it's a heart-wrenching experience. It's a curse, that illness. I don't want my own enemy to have the mental illness.*
> Divan: *Mm hm. Your whole life is turned upside down?*
> Skollie: *I wouldn't wish it on my own bloody dog, this mental illness.*

Thus, it was not surprisingly when he reported caregiver burden in various domains. Despite his sense of feeling obligated to look after his children, it was unpleasant for Skollie to have his children at home, and he specifically shared with me the strain that having to care for a person with schizophrenia has put on his relationship with Sheila. Moreover, he also referred to the financial strain that caregiving posed to the family, and the difficulties related to institutionalising a person with schizophrenia for a prolonged period of time. Skollie utilised various coping strategies to handle the demands of being a schizophrenia-caregiver. For Skollie, his recreational activities played a fundamental role in helping him to "break away" during difficult times. Additionally, through accepting his situation offered him peace on an emotional level. Lastly, religion and having a life partner in Sheila were two important factors that contributed to Skollie's sense of coping with being a caregiver.

Sheila

Sheila was married to Skollie at the time of the interviews and therefore their caregiver context was the same in most ways regarding their children. Sheila has always been a house wife and reported that she has been caring for her daughter with schizophrenia for 15 years. One of the major challenges for Sheila during this time was the fact that Skollie was often away working and she had to attend to caregiving on her own. Sheila also reflected on the strain that caring for children with schizophrenia introduced to her marriage. Despite the contextual similarities, Sheila produced unique narratives. During the interview she shared deep feelings of guilt, as she felt that it was her fault that both her children have schizophrenia. She further also shared that since her children's diagnosis, her health has deteriorated significantly. For Sheila caregiving introduced both an emotional and physical burden. In terms of physical burden, her sleep was frequently disrupted by her daughter during the symptomatic phases of schizophrenia. Like other caregivers in the study Sheila also drew on her "strength" to cope during difficult times. However, she was the first participant to report coping by educating herself regarding schizophrenia and illness related aspects as a problem focused coping strategy. Social support from community members was also a factor that facilitated her coping during difficult times.

Doris

Doris was, at the time of the interview, a married housewife and mother of three – a son, and two daughters who both experienced psychosis. However, only one of her daughters was diagnosed with schizophrenia. Both daughters lived in Doris' house. During the interview Doris explored how easy it was for her to look after her daughter with schizophrenia. Two justifications were offered for this. First, Doris' daughter has insight about her illness and adheres to her antipsychotic medication regime. Second, her daughter offers her a sense of companionship, assisting her with daily tasks. Furthermore, Doris explained that because of her age she often tends to be forgetful, but that her daughter frequently supports her by reminding her when she forgets. However, Doris also reported a number of burdens from having her daughter living at home. One of the burdens that Doris vividly shared was the burden of having to witness her daughter during distressing times caused in the symptomatic stage. Not only did Doris have to witness the distress, but also had to assist her daughter and actively care for her during these times. She explained this during the interview:

> Doris: *Dan moet jy maar geduldig wees [pouse] party dae was dit moeilik [pouse] want dan't sy gekla dat sy brand, en hulle krap vir haar [Dawn se ervarings] of sy is*

te siek dan moet ek vir haar iets smeer, al daai dingetjies wat ek in die aande vir haar gedoen het en in die oggend as ek werk toe gegaan het.
Divan: *Mmm, jy't gesê hulle krap haar en sy brand?*
Doris: *Ja sy brand [bevestigend]*.
Divan: *Waarna verwys dit, hoe't dit gebeur?*
Doris: *So sy't siek geraak. Sy't skool gegaan nog. Sy was graad elf. Toe't sy nou vir my vertel iemand krap haar, krap vir haar en sy brand [pouse] dan moet ek nou vir haar mecu- mecurocram lappe op haar sit en laat die… die warmte moet weggaan die brand net kan weggaan. En haar rug, dan is daar rêrig krappe op haar rug, sulke krappe wat so oral…*

Doris: *Then you have to be patient [pause] some days it was difficult [pause] because then she complained that she was burning, and they are scratching her [Dawn's experiences] or she is too sick then I have to rub something on her, all those things that I did for her in the evenings and in the mornings when I went to work.*
Divan: *You said they scratched her and she was burning?*
Doris: *Yes she is burning [confirming]*.
Divan: *What does that refer to, how does that happen?*
Doris: *So she became sick. She was still going to school. She was grade eleven. Then she told me someone was scratching her, scratching her and she is burning [pause] the now I have to put mecu- mecurocram cloths on her so that the- heat must go away burning can just go away. And her back, then there are really scratches on her back, such scratches that are everywhere…*

Additionally, stigma was another burden experienced by Doris. People commonly referred to psychiatric institutions as "malhuise" (crazy-houses); this introduced a sense of worry and shame for Doris. At the time that Doris shared this stigma related information with me, I was aware of the frustration that I experienced – I suspect that my frustration was caused by the conflict between my biomedical viewpoint on a person with schizophrenia vs. society's discrimination and discrimination against patients. Another reason may be attributed to the fact that I had a cousin who lived with schizophrenia, and in this moment I realised, that is how members of the community may refer to him – being a crazy person. On the coping spectrum, Doris predominantly utilised emotion focused coping strategies of acceptance, being patient and staying calm during moments of stress, and finding gratification from her

role as caregiver. Lastly, Doris confirmed the importance of healthcare services when she valued the assistance that she received from healthcare services that cared for her daughter, as this facilitated her daughter's well-being and aided coping.

Betty

Betty was the mother of a son with schizophrenia. She was divorced, part-time employed by the city council of the Western Cape, and her children were living with her in her house. During the informed consent procedure her son displayed delusions of grandeur. What struck me at this stage was Betty's non-confronting interactive style towards her son, as she calmly went about enjoying the refreshments that were available, while her son dominated verbally in the welcoming room. In her interview she explained that one of her emotion focused coping mechanisms was avoiding confrontation with her son. Betty further, proudly explained how her son was favoured by many members in their community. Social support from family and community members was thus a fundamental coping agent for Betty – not only did members of the community offer emotional support during difficult times, but also, outsiders acted as social informants of her son's behaviour, the "eyes of the caregiver" when Betty could not be with him. Despite feeling greatly supported by others, Betty also reported difficulties that she faced while having to care for her son. Betty's narratives mostly indicate the difficulties arising during the stages when her son was in the symptomatic stages of schizophrenia. She was the only caregiver who reported that she feared that the patient with schizophrenia might commit suicide; she explained:

> *Ek het gedink, hy pla nou aan met sy lewe, hy wil hom gaan verdrink, wat maar ook so sê, maar- wil hy hom gaan verdrink, "hoekom wil my kind by ŉ beach toe kom," want nou dink ek ook...*
>
> *I thought, he's bothering on with his life, he wants to go and drown himself, which also says like, but- he wants to go and drown himself, "why does my child want to come to a beach," because now I'm also thinking…*

Furthermore, the numerous hospital visits that Betty had to attend with her son introduced challenges of their own. Not only did this disrupt her, already inconsistent, career responsibilities, but also she found that general healthcare practitioners could not make an appropriate schizophrenia diagnosis at the time. When I heard this information I was surprised, as Betty was only the second participant out of six caregivers to report this barrier

to effective mental healthcare in the physical healthcare domain. Thus, at this stage, I felt the need to probe for similar narratives if the opportunity arose in following interviews.

Charlie

Charlie was a widowed father of two whose one son had been diagnosed with schizophrenia. He had also retired from his work and spent most of his days at home or with friends. During Charlie's interview three aspects of his life struck me. First, the grief for his late wife that he was experiencing appeared to be a daily process for Charlie. Second, how Charlie portrayed himself as a person who by nature invests and offers support to others. Third, at the time, Charlie was experiencing great difficulties with having to deal with his son at home – it was his son's obsessive and compulsive behaviours (APA, 2013) that challenged Charlie on a daily basis. It appeared that, for Charlie, social support from his friends and family played a fundamental role in helping him cope with the difficult times. This was confirmed when he shared that he was planning a holiday to New Zealand – where Conrad's brother lived. At times I asked myself – *I wonder if Charlie will indeed enjoy the breakaway?*; as worry seemed to be an ever present emotion for Charlie:

> *En, ek kan hom nie [pouse] partykeer as ek iewers heen gaan dan, ek worry baie want, ek weet nie ek kan hom nie alleen los nie… Hy weet nooit waar sy lighter is nie, ek koop partykeer twee lighters vir die dag, sulke goed, as hy sigarette, dan vat, sit hy neer, dan weet hy nie… want, want elke keer, my stoof noudie dag skoongemaak, dan't hy 'n lighter, want hy kry nie sy lighter nie, dan light hy die oond, of in my… Die plaat was aan eendag, die [pouse] die handdoeke was aan die brand toe ek by die huis kom, sulke goed.*

> *And, him I can't [pause] sometimes if I go somewhere, I worry a lot because, I don't know I can't leave him alone… he never knows where his lighter is, I sometimes buy two lighters for the day, stuff like that, if he has cigarettes, then he takes, he puts it down, then he doesn't know… because, because every time, cleaned my stove the other day, then he has a lighter, because he can't find his lighter, then he lights the oven, or in my… the stove plate was on one day, the [pause] the towels were on fire when I got home, stuff like that.*

Zuby

Zuby was a divorced mother of two sons and was at the time of the interview employed on a full-time basis. In her interview, she explained how she had moved from the Eastern Cape to Cape Town at the time of Peter's schizophrenia onset. Managing numerous life stressors posed challenges for Zuby. However, she frequently reflected the great improvements that have occurred in her personal life and that of Peter's since moving to Cape Town. According to her Peter had overcome various challenges that schizophrenia introduced, and developed into a confident and independent individual who held a full-time job. It seemed to me that most burdens that schizophrenia introduced to her life were now more reflections of the past, and not present experiences. This might be confirmed by the fact that thematic analysis of her interview generated, relatively, fewer codes on caregiver burden compared to other participants' stories. For Zuby, her religion, social support at work, and attempts to gain understanding about the schizophrenia facilitated her coping. She further also reported experiences of personal growth – these I associated with her perceptions of the high functioning patient. She narrated this:

> *And it shows you that they build up- they're starting to build up their self-confidence. I noticed that also in the sense that he wasn't taking care of himself, that he was now actually trying to take care of himself, you know, buying his toiletries which he never did before, you know, on his own, let me put it that way, his clothing, he never did before, we did it. Now he actually goes and do his- buys his own clothing. That- all that type of thing, him taking care of himself is important now for him, which he never did before. There was days where he didn't even want to bath.*

Natalie

Natalie was the sister of a person with schizophrenia. She was also a mother of twin daughters. Together with Brett they were all living with Natalie's mother, who also participated in my study – Betty. What stood out for me during the interview was Natalie's empathy with her brother's situation. She proudly spoke about how she utilised her training as a lay-healthcare worker to facilitate interactions with her brother. Her background as a healthcare worker also enhanced her coping with the demands of caregiving. Additionally, religion, social support from family, friends, and members of the community enhanced her coping experiences. Natalie reported caregiving burden on different levels. She frequently had to engage in new and additional activities – especially when her mother was at work. Due to these moments of being sole caregiver, she also experienced burden in this domain – being the only caregiver. Furthermore, she was also challenged by Brett's problematic

behaviour. She also feared her brother's actions when he displayed odd and aggressive behaviours.

Jack

Jack was a security guard and the boyfriend of a female with schizophrenia. Together, they had one child, who at the time of the interview appeared to be between one and two years of age. All three individuals were present at the informed consent procedure before Jack's interview commenced. It was then that I realised that Jack might be the only caregiver for both the baby and Jessica. I wondered, if this were the case, how he managed this role(s) while being the only income producer in the triad. During his interview, Jack spoke about the heartache that he experienced during the onset of Jessica's schizophrenia. However, I found it difficult to interact with him as Jack could not communicate in Afrikaans and our English vocabulary, at times, was not mutually understandable. Nevertheless, I perceived him as a confident, strong-willed individual who chose not to back down from challenging encounters. His caregiving acts seemed to be problem-solving orientated as he committed himself to the responsibility. For me, his attitude as caregiver was summarised by the following words he voiced:

> *No, you know mos, every- even- even you know, maybe it's not here when someone is not- is not all right you can't feel happy, you see, so you have to make a plan to- to get her some doctor or any- or any help, you see?*

Zelda

Zelda was married, a mother of two sons – one who had been diagnosed with schizophrenia. She was also full-time employed as an accountant in Cape Town, approximately 30km from where she lived. My impressions of Zelda started to form during my phonecall to invite her to join my study. During this interaction she sounded as if she had had enough of Mark's problematic behaviour, which was fuelled by his drug abuse. She stated that she had kicked him out of the house and obtained a restraining order against him – the reason for this was that he had been stealing from home and sold Zelda and her husband's property to buy drugs. At her interview, she came across as a woman who was seeking an ear that could listen to her story. Thus, I was not surprised that her interview was the longest of all caregivers' in my study. She further reported burdens in multiple domains such as encounters with schizophrenia-related behaviours and the new activities that she had to engage in as caregiver. She also reported on the emotions of loss, disappointment, and worry that she

frequently experienced. During data analysis, I found it interesting that Zelda was also ambivalent towards Mark – was he as difficult as how she initially portrayed him to be?; also, has she had had enough of his problematic behaviour, or could she continue to care for him at home? It also seemed as if she was longing to take her son back in, but was also fearing her husband's reaction to this. Coping through religion, and social support resources – friends and family, police and mental healthcare services was identified. What struck me towards the end of our interaction was Zelda's emotional strength and her hope for Mark's recovery.

Olivia

Olivia was a married mother of a son with schizophrenia. She had been retrenched from her work and was unemployed at the time of the interview. She explained that her only income was generated from being caregiver of her daughters' three children. What struck me about Olivia was that she appeared older than her age of 53 years. Later, when she spoke about various personal mental and physical difficulties that she was experiencing, I wondered if her older-than-her-age appearance had not resulted from these health complications. Furthermore, Olivia was deeply emotional during her interview – at times I thought it best to cut short the interview; however, she insited on continuing the interaction. Transcription showed that she had used the word "swaar" (heavy) a total of 20 times during her 45 min interview. This really affected me emotionally, as I could not help but think about my aunt who also provided care for a person with schizophrenia. Yet, I do believe that my counter-transference did not negatively affect the outcome of our interaction. It was this moment when I realised that not all caregivers experience patients as "easy patients". I also perceived Olivia as a mother who experienced intense hearthache about her, her son, and the rest of their family's situation. She reported that she received little-to-none support from other family members beside her husband and daughters, and that the rest of the family commonly treats Alfred as inferior because he was "different". Thus, it was expected when analysis indicated that her husband was one of her coping resources. Olivia was burdend with her son's drug abuse, and problematic behaviours. Yet, she shared that she belived in providing care with love and tried including Alfred in her everyday life.

Suzette

Suzette was a full-time employed, single mother of a son with schizophrenia. She appeared withdrawn at first, but later warmed to communicating. In her interview, I sometimes wondered if she had hesitated to interact and to answer the questions posed. I found myself

questioning my approach of interviewing her, but remained calm and polite throughout – making use of reflections, paraphrases, and constant eye contact throughout the interview. Suzette was experiencing difficulty in accepting her son's illness; I attributed this to her lack of knowledge of schizophrenia, but also to her lack of understanding about the functioning of antipsychotic medication. Suzette voiced that, since Fred initiated antipsychotic treatment, he has recovered from schizophrenia; and at times she wondered if he still needed to take the medication. She stated in our interaction:

Divan: *En wil teruggaan. Jy sê vir my partykeer dink jy Fred het nie skisofrenie nie.*

Suzette: *Ja.*

Divan: *Wat laat jy so dink?*

Suzette: *Omdat... vandat hy hierna gediagnoseer is met skisofrenie en vandat hy op die pille is, van 2010 af is daar- het ek nog nie een oomblik opgelet het- of het hy nou al iets gedoen wat hy nie moet doen of so, of...*

Divan: *So ek dink vir hom die pille- vandat hy op die pille is het sy lewe verander, of sy siek wees verander?*

Suzette: *Kyk, hy was oor die algemeen 'n baie rustige kind.*

Divan: *Okay, dis nou voor die pille?*

Suzette: *Voor hy skiso- voor hy gediagnoseer is met skisofrenie, en in daardie tyd terwyl hy gediagnoseer was met skisofrenie, toe was hy nou 'n bietjie baie... hoe sal ek sê- toe was hy nou 'n bietjie baie... woelig, en so ek moet hom nou net dopgehou het en kyk ek waar gaan hy en so- O, maar vandat hy op die pille, op die pil is, of Clozapine is, is hy baie, baie rustig. Somtyds dan dink ek, en wonder of hulle hom nie maar hom nie af van die pille gaan haal, of...*

Divan: *So jy het daardie- daardie wonder in jou?*

Suzette: *Ja, want ek het rêrig- ek het- ek het glad nie 'n probleem nie met hom, met...*

Divan: *And want to go back. You tell me sometimes you think Fred doesn't have schizophrenia.*

Suzette: *Yes.*

Divan: *What makes you think that?*

Suzette: *Because… Since he's been diagnosed with schizophrenia and since he's been on the pills, since 2010 there is, I haven't noticed for one moment that- if he has done something that he mustn't do or so, or…*

Divan: *So I think for him the pills, since he's been on the pills his life has changed, or his being ill has changed?*

Suzette: *Look, he was generally a very calm child.*

Divan: *Okay, that's before the pills?*

Suzette: *Before he schizo- before he was diagnosed with schizophrenia, and in that time while he was diagnosed with schizophrenia, he was a bit very… how will I say- then he was not a bit very… busy, and so I just had to keep an eye on him and I watched where he was going and so on- Oh but since he's on the pills, or on the pill, or Clozapine, he is very, very calm. Sometimes I think, and wonder if they aren't going to take him off the pills, or…*

Divan: *So you have that- that wonder in you?*

Suzette: *Yes because I really- I did- I don't have a problem with him at all, with…*

In her last narrative she stated that she experienced no problem with Fred. Yet she interestingly reported various caregiver burdens during the interview. She experienced shock and uncertainty, while she encountered aggressive and drug abuse patient behaviours at home. Moreover, problematic behaviours were a prominent theme that emerged during analysis of her interview. Against this Suzette also utilised various problem and emotion-focused coping strategies as caregiver. Social support in talking to others (e.g., family) contributed to enhancing her emotional well-being and she relied on her son's antipsychotic medication adherence as well. Emotionally she also engaged in avoidant thinking patterns.